

A Week in the Life of Community Programs:  
Describing Barriers Experienced by Three Transition Age Youth with Autism Spectrum  
Disorder and their Caregivers

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## Abstract

Various barriers for participating in physical activity for people with Autism Spectrum Disorder (ASD) have been identified; specifically, the insufficient availability of programs and knowledgeable personnel to run them (Taub & Greer, 2000; WHO, 2015). Ironically, there are a magnitude of proven benefits specific to ASD that accrue from being physically active, including a decrease in stereotypic behaviours (hand flapping, object spinning) and sleep deprivation (Taub & Greer, 2002; Todd & Reid, 2006; Gaskin, Anderson & Morris, 2009; Connolly, 2008). Previous research has focused on investigating barriers for individuals experiencing disability in relation to environment, economic and political components (McDermott & Turk, 2011). However, minimal research involves the perspective of the individuals experiencing ASD who do not use verbal communication and require greater supports.

The purpose of this phenomenological study was twofold. Firstly, to unearth barriers experienced by three transition aged youth with Autism who require 1:1 support or greater and their caregivers in a 'typical week'. Secondly, to examine whether Priestley's (1997) 6 principles of emancipatory research could be applied to this research process.

In the process of engaging with the three youth participants and their caregivers in this study, I completed multiple observations of the youth participants in community programs and activities, then conducted semi-structured interviews with their caregivers, and non-traditional, alternative communication interviews with the youth participants.

Analysis revealed that implementing Priestley's 6 principles of emancipatory research could not be applied to this research process because of controversies with the ethics board. As well, barriers to participation in community programs included lack of staff training and inability to adapt to individual needs.

The findings of this study imply a greater need for rapport based and embedded research with individuals experiencing complex ASD. Similarly, Research Ethics Boards need a greater understanding of individuals who do not use words to communicate to enable researchers to pursue authentic emancipatory research with complex and typically, under-represented participants.

## Table of Contents

List of Tables .....	vii
List of Figures .....	viii
Chapter 1: INTRODUCTION.....	1
Background and Researcher Perspective .....	1
Purpose and Research Questions.....	4
Chapter 2: REVIEW OF LITERATURE .....	5
Autism Spectrum Disorder.....	5
Previously Identified Barriers .....	7
Benefits of Participation in Community Programs .....	9
Transition Age Youth (TAY).....	11
Critical Disability Studies .....	12
Reimagining the Triad of Impairments .....	14
Framework for Emancipatory Research.....	17
Chapter 3: THE RESEARCH DESIGN .....	21
Hermeneutic Phenomenology .....	21
Consent and Procedure.....	22
Participant Recruitment.....	23
Data Collection.....	24
Data Analysis .....	26
Thematic Analysis.....	27
Collaborative Analysis .....	28
Existential Analysis.....	28
Trustworthiness: Prolonged Engagement and Ethical Considerations .....	29
Chapter 4: FINDINGS .....	31
Findings: A Week in the Life.....	31
Adam .....	31
Chester .....	33
Keira .....	36
Findings Ethics: “Is it unethical to be ethical?” .....	39
Theme: <i>Researcher Role(s)</i> .....	39
Theme: <i>Unquestioned starting point</i> .....	41

Interview Findings.....	42
Theme: <i>Community vs. Crowds</i> .....	42
Theme: <i>The “Professionals”</i> .....	44
Theme: <i>The “Out of Control” Body</i> .....	46
Observation Findings .....	49
Theme: <i>Individualized Programming</i> .....	49
Theme: <i>Who’s Working Today?</i> .....	52
Theme: <i>Programming Insights and Supports</i> .....	52
Life world Existentials .....	54
Chapter 5: DISCUSSION .....	59
What experiences are constituted as barriers?.....	59
“The Professionals” .....	59
The “Out of Control” Body .....	60
Which barriers experienced have the greatest impact on participation in community programs? .....	64
Can Mark Priestley’s 6 principles of emancipatory research be applied to the research process? .....	65
“Is it unethical to be ethical?”.....	65
Limitations and Future Directions.....	69
References .....	71
Appendix A.....	81
Appendix B .....	82
Appendix C. ....	83
Appendix D.....	84
Appendix E. ....	87
Appendix F.....	90
Appendix G.....	92
Appendix H.....	93
Appendix I .....	97
Appendix J .....	98

List of Tables

Table 1. ....	23
Table 2. ....	32
Table 3. ....	34
Table 4. ....	37
Table 5. ....	38

List of Figures

Figure 1: Research implications.....	70
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*“People with disabilities who are frequently in crisis are given “severe reputations” by the system that is supposed to support them. They are trapped by ways of listening and understanding that are too narrow; ways of listening that hear a need for control rather than complaints about their services.”*

Michael Smull (2000)

## Chapter 1: Introduction

### Background and Researcher Perspective

I have been working with people who experience Autism and other neuro-diversities for the past five years. I have been in several roles throughout these years such as, respite worker, program support staff, program assistant, and researcher. Given my diverse background working as a professional in various capacities, I have gained valuable insights into the world of community programs. It is my experiences working in these various roles that has brought me to this current study, specifically one crucial moment when I was near the beginning of my journey into this field.

A few summers ago, I was given the opportunity to spend my summer as a respite support worker with a young adult with Autism Spectrum Disorder (ASD). We would spend four days a week together doing various recreational activities each day. A few weeks in to my new job, I had an idea for us to try an art class. I informed her mother about this art studio I had found online, the times we could go, and the prices. I ensured I had all the details prepared for this new activity to go smoothly. Quickly after sending this message to her mother, she replied asking me if I had called and informed them that her daughter has Autism; my first thoughts were: *“why do they need to know this before we arrive? Will they turn us away because she has Autism?”*. As my mind raced through these questions, I picked up the phone and called anyway. To my delight, this facility was more than welcoming of all abilities. However, from that moment on, I could not shake the thought of her possibly being ‘turned away’ from public facilities because she has Autism.

Prior to this experience I had never considered needing to call programs or facilities to check if they are ‘okay’ with someone with Autism attending, and now I find myself doing it

often. Reflecting on this one crucial experience, I began to wonder what other *'barriers'* individuals with ASD experience? And how many adaptations must they make to be *'accepted'* in public spaces rather than public programs accommodating their needs?

An article written by Goodwin, Johnston & Causgrove Dunn (2014) examined ethical issues regarding inclusion in recreation sport. The authors retrospectively unwrapped an event referred to as “Jack’s Story”, written from the perspective of Jack’s support worker. This story begins to unearth barriers people with ASD experience when participating in physical activity. This story unravels a regular visit to the local YMCA. The worker explains how Jack was excited to be at the facility and was expressing himself with his unique sounds, jumping and flailing his arms; all of which are common characteristics associated with autism. While expressing his excitement, an older man in the changeroom approached Jack’s worker “looked directly at [the worker] ignoring that Jack even existed and began to say in the most hate filled and annoyed tone of voice, ‘Fucking shut him up!’” (Goodwin, Johnston, & Causgrove Dunn, 2014. pp. 22). Jack’s dignity was violated when this individual not only disrespected him and the way he expressed himself but proceeded to overlook Jack and ignore his existence as a human being. This is a significant contributing factor to understanding barriers experienced by many people within the ASD community in everyday life.

The findings of this article clearly address the need for society to adapt to and accommodate these participants and welcome their differences. These findings support “the social model” identified by Cameron (2014), which explains individuals with impairments only become disabled by “poor or non-existent access to public places where ordinary life happens...” (p. 137). This model was clearly confirmed with Jack’s story and furthers the need to unearth the barriers developed by society which restrict participation in many spaces and facilities.

Although “Jack’s Story” exposes crucial components of the experience, this story was told by Jack’s support worker through his interpretation of the event. Currently, research about barriers experienced by transition age youth with ASD requiring significant support, is minimal. More specifically, existing literature has been interpreted by an outsider (someone who does not share the experience of ASD). Research examining individuals experiencing disability from an ‘outsider’ perspective is a defining element of the study of disability compared to ‘disability studies’. Previously, the study of disability was criticized for embracing a “medical model” approach to research which has contributed to the depiction of disability as a personal tragedy (Cameron, 2014) in which people with impairments are ‘pitied’ because of their bodies. Since acknowledging the stigmatized responses and outcomes of this model, researchers have begun to advocate the moral and ethical importance of listening to the stories by those who experience disability (Smith & Sparkes, 2009). Specifically, this paper will later focus on critical disability studies (CDS) scholar, Mark Priestly WHO developed principles of emancipatory research (Priestly, 1997) to assist future researchers to adopt these moral and ethical practices in their work.

For this study, I worked within a constructivist orientation to research, engaging a Critical Disability Studies theoretical framework and a phenomenological approach to analysis. I worked within a constructivist orientation because I believe objectivity is impossible and that “meaning is constructed as a result of interaction between humans and their world” (Crotty, 1998. In Jones, Torres & Arminio, 2013.). I believe each person’s experiences and perspectives are socially constructed from their interactions within the world. Similarly, I incorporated a Critical Disability Studies theoretical framework. This framework adopts the social model which views disability as socially constructed and a person’s interactions within the world is what

disables them. Through this framework I attempted to follow Mark Priestley's 6 principles of Emancipatory research which values the voice of the people experiencing the phenomenon and strives to develop research that will benefit them, not just the researcher. Lastly, I use a phenomenological approach to analysis to create rich descriptions of the phenomenon to share the experiences of the people living it. Additionally, I included Van Manen's (1990) lifeworld existentials lived body, lived space, lived time, and lived human relation, to get a greater understanding of their experiences within their worlds.

### **Purpose and Research Questions**

Thus, in my research study, I strived to integrate the lived experiences of three (3) transition age youth by sharing their stories as well as the caregiver's personal interpretation of the shared experience. The purpose of this phenomenological study is to unearth barriers experienced by three transition aged youth with Autism and their caregivers in a 'typical week'. To have a deeper understanding of this experience, I must break down the typical week to identify the barriers present and their effect in their everyday lives. I have developed three questions to address the various components of my research, which include:

- 1) What experiences are constituted as barriers?
- 2) Which barriers experienced have the greatest impact on participation in community programs?
- 3) Can Mark Priestley's 6 principles of emancipatory research be applied to the research process?

## Chapter 2: Review of Literature

### Autism Spectrum Disorder

In 1943 a child psychiatrist, Leo Kanner published a paper discussing a group of children under 11 years of age with *fascinating peculiarities*. Kanner had been following and analysing these individuals since 1938 and although each child presented different characteristics, a few commonalities were transparent. Specifically, the *inability to relate themselves to people and situations*, inability to use *language to convey meaning to others*, repeating *personal pronouns as heard*, and an *obsessive desire for sameness* (Kanner, 1943; original words italicized).

Since Kanner's findings, the diagnostic criteria of Autism have changed in conjunction with the rising population of person's with ASD. In 2010, the National Epidemiological Database for the Study of Autism in Canada published a consensus identifying the prevalence of children diagnosed with ASD to be 1 in 94, with a ratio of 4:1, males to females respectively.

With the increased prevalence of ASD, many other characteristics were added to Kanner's original findings; including but not limited to: difficulties with developing and maintaining relationships, repetitive movements and behaviour patterns, intense fixated interests, and hyper- or hypo-reactivity to sensory stimuli (Copeland, 2018. *American Psychiatric Association*).

Recognizing the varying presence and complexity of characteristics between people, makes developing a single definition which captures all unique traits very difficult. However, a recent (and broad) definition explains ASD as a complex developmental condition which involves challenges with communication, social interaction and repetitive behaviours (Copeland, 2018.) Everyone with ASD experiences it differently and therefore, the way a person

communicates, thinks, and interacts within the lived world can vary greatly from person to person.

Our knowledge and understanding of ASD is continuously growing and shaping. Recently, the prominence within the literature focusing on motor “deficiencies” is a budding area of interest recognized by researchers, practitioners, and parents. These delays are often first recognized as early as 6 months (Connolly, 2008; Ornitz, Gurthrie, & Farley, 1997; Todd & Reid, 2006) and minimal opportunity to engage in physical activity further hinders development of these skills.

Along with reduced opportunity, people experiencing ASD live within bodies which are greatly impacted and stressed by external stimuli. Living within stressed bodies often results in communication and expression through various body movements and coping behaviours. However, because this is a non-traditional mode of expression they are often prescribed a variety of medications to reduce these behaviours for them to interact in society ‘normally’. To obtain this sense of ‘normalcy’, many individuals are given antipsychotic drugs to minimize these behaviours which has proven to result in a 5.4kg weight gain during six months of treatment (Srinivasan, et al. 2014).

Acknowledging the magnitude of complex characteristics, and management techniques which contribute to movement challenges and weight gain as previously discussed, emphasize the need to further understand their lived experiences to open opportunities for participation in physical activity.

## **Previously Identified Barriers**

As previously discussed, the complexity of this disorder often results in significantly greater sedentary behaviours because of the insufficient availability of programs and knowledgeable personnel to run them (Taub & Greer, 2000; WHO, 2015). The significantly low levels of physical activity among youth with ASD was highlighted by the Council on Children with Disabilities Executive Committee of the American Academy of Pediatrics (AAP). This committee recommended that youth with disabilities must increase participation in physical activities by eliminating societal barriers, emphasizing the role of health professionals to advocate for participation in sport (Rimmer & Rowland, 2008). This report further urged children with disabilities to become more involved in competitive sport (Murphy & Carbone, 2008). On the contrary, it has been noted that team and competitive sport often have a negative impact on individual's experiences; mainly due to lack of motor competence resulting in decreased participation and less meaningful engagement (Beni, Fletcher, & Ní Chróinín, 2016).

The significant focus on social interaction, movement performance, and competency with complex motor skills within sport will potentially be problematic for individuals experiencing ASD (Todd & Reid, 2006). Given the complexity of ASD and the resulting motor functioning, coordination challenges (Reid, O'Connor, & Lloyd, 2003; Lang, et al., 2010; Connolly, 2008) and social impairments, meaningful participation and enjoyment may be minimal.

Many identified barriers experienced by youth with ASD in the literature are regarding their characteristics and demeanor. Previous literature has noted difficulties coping with various auditory, visual, and tactile stimuli may be other contributing factors to the lack of participation in physical activity programs (Connolly, 2008; Rosenthal- Malek & Mitchell, 1997) and thus, community programs in general. Individuals experiencing ASD and various other disabilities,



often struggle with social skills and communication resulting in them finding different forms of communication which is often viewed as “behaviours” by many staff and community members. Specifically, one study found that children with disabilities who struggled with social and behavioural skills were asked to leave community recreation programs (Jones, 2003). Within the literature the barriers identified such as “problem behaviours”, or “social impairments” as previously discussed, in my opinion, are not adequate barriers, these are characteristics which can be adapted too with knowledge and training.

Likewise, other barriers identified are the insufficient availability of inclusive community and physical activity programs, lack of knowledgeable staff, (Jones, 2003; Obrusnikova & Cavalier, 2011; Schleien, Germ, & McAvoy, 1996; Taub & Greer, 2000; WHO, 2015; Moran & Block, 2010) and staff attitudes (Jones, 2003). Stanish, et al., (2015) investigated physical activity enjoyment and perceived barriers through direct reporting from adolescents with and without ASD, and parental perceived barriers. The perceived barriers identified by the youth with ASD were consistent with previous research and included lack of access P.A. programs, minimal enjoyment in group activity settings and inadequate facilitators running the programs (Taub & Greer, 2000; WHO, 2015). Similarly, Jones (2003) conducted a study with parents of children (ages 5-35) with disabilities examining barriers to participation in community recreation programs and highlighted two barriers found in previous literature which consisted of negative staff and community attitudes as well as staff knowledge and awareness about disabilities. They further explained the parent’s frustration with the lack of access to community programs because of the staff’s lack of knowledge and “ignorance of how to program for children of varying abilities” (Jones, 2003. p. 60). This finding further supports my argument that individual characteristics should not be viewed as barriers, the inadequate training and knowledge of staff

to properly accommodate each person seems to be the most prominent barrier within the literature. Community and societal barriers have led to the most disabling environments and are a cause for concern regarding participation in community programs.

### **Benefits of Participation in Community Programs**

*‘Through participation, we acquire skills and competencies, connect with others and our communities and find purpose and meaning in life’. (Law, 2005)*

Along with the magnitude of barriers previously discussed, individuals with ASD often live significantly sedentary, isolated lifestyles, which is often associated with their intense fixations, challenges with social interactions, ‘stereotypic behaviours’ and limited knowledgeable personnel to adapt to the diverse characteristics of ASD. However, in conjunction with reduced physical activity levels, Srinivasan, et al., (2014) and McCoy, Jakicic, & Gibbs, (2016) identify three factors which potentially contribute to the occurrence of obesity among individuals experiencing ASD. These factors include: poor nutrition, medication use and metabolic abnormalities and lack of knowledge regarding healthy living. Medication is previously identified in this paper as a significant contributor of weight gain, however, poor nutrition is an interesting factor which should be considered. Given the manifestation hypo- or hypersensitivity to sensory stimuli as well as greater oral sensory sensitivity (Chistol et al., 2018) experienced by people with ASD. These sensory sensitivities can affect one’s diet because it is possible some textures are unbearable to the touch, some smells may be painful, some colours may be utterly disturbing, and maybe only specific colours are meant to be eaten? The rationalities are endless, however, avoidance or over indulgence of various foods can be a

contributing factor of weight gain. Similarly, people experiencing ASD often struggle with social skills

With the increased knowledge of various risk factors associated with weight gain, and obesity research is progressively developing and investigating the physical activity as an intervention to manage “autism- specific impairments” which includes aggressive or “problem” behaviours, stereotypical actions (Srinivasan, et al., 2014) along with the abundance of other benefits associated with physical activity. A meta-analysis conducted by Sowa & Meulenbroek (2012) analyzed 16 studies and determined, on average, exercise interventions led to a 37% improvement in ASD related “symptoms”. These findings were also consistent with previous research using a vigorous intensity exercise intervention (i.e. jogging, roller-skating, etc.) and found a substantial reduction in aggressive or self-injurious behaviours (Lancioni & O’Reilly, 1998; McGimsey & Favell, 1988; Taud & Greer, 2002; Todd & Reid, 2006; Connolly, 2008).

The list of P.A. benefits is exhaustive and greatly emphasizes the need for more adaptive and inclusive P.A. programs. However, this study is looking at all forms of community programs which have similar benefits associated with participation. Although evidence supporting the benefits of P.A. is unlimited, there is minimal research examining the benefits of community and recreational program participation for transition age youth experiencing Autism. Research has proven that participation in recreational and community programs helps children with impairments “develop friendships, optimize physical functioning, improve self-esteem and enhance overall well-being” (Dyken, Rosner, & Butterbaugh, 1998; Murphy, & garciaCarbone, 2008 in Gossett & Tingstrom, 2017. p. 31.). Similarly, other studies conducted with adolescents and adults with ASD have found leisure participation “decreases distress, increases positive affect, sustains efforts in coping, increases social involvement, improves access to social

supports and promotes positive responses to difficult situations” (Garcia-Villamisar & Dattilo 2010; Turygin & Matson 2014 in García-Villamisar, Dattilo, & Muela, 2017. p. 325). Seeing the benefits correlated with participation in leisure, physical activity and community programs, and considering the increased levels of stress and anxiety experienced by people with Autism (e.g. Green et al., 2000; Kim et al., 2000; Gillot et al., 2001; Bellini, 2004), as well as findings stating that they have higher levels of loneliness (Huang & Wheeler 2006), it is evident that there is a greater need for community programs available to support the participants.

### **Transition Age Youth (TAY)**

Transition age youth is the age where individuals leave the entitlement of children’s supports and services and transition into underfunded adulthood, typically between the ages of 18- 22 (Friedman, Warfield & Parish, 2013). This period is often referred to as the “service cliff” because of the limited availability of appropriate adult services (Roux, et al., 2015). This “service cliff” and the resulting gap in programs and services is the main reason this group was chosen for this research. One study reported TAY with autism had significantly lower quality of life scores regarding social support and peers, physical wellbeing and psychological wellbeing (Biggs & Carter, 2016). These lowered scores may be influenced by the limited involvement in extracurricular activities and community activities which results in less opportunity for social engagement and relationship development (Shattuck et al. 2011). This limited involvement in community activities is significantly related to the lack of services and supports available. Similarly, a review of literature conducted by Hendricks & Wehman (2009) found most adolescents with ASD live with their parents and are dependent on them into adulthood. These findings, like the lack of involvement in community activities, further supports the need for more

awareness of these challenges to offer programs and services to the adolescents and young adults.

Currently, the research focusing on barriers experienced by TAY with ASD in community programs is limited. As previously mentioned, there have been studies conducted examining barriers experienced by adolescents and young adults with ASD (Hamm & Driver, 2015; Stanish et al., 2015). However, the participants in these studies use words to communicate and do not require significant supports. The remainder of articles I found discussing barriers to community programs were focused on children's supports (Obrusnikova & Cavalier, 2011; Obrusnikova & Miccinello, 2012; Schleien, Miller, Walton, & Pruett, 2014). This further highlights the need for research including TAY experiencing ASD with complex needs.

### **Critical Disability Studies**

Before explaining the principles for the model of emancipatory research I aim to be implementing, I feel it is crucial to begin with an explanation of Critical Disability Studies to understand the importance of adopting this CDS framework in my work. Disability studies began with disabled people fighting for their rights with minimal success, until Mike Oliver's development of the social model was released. Mike Oliver identifies as a disabled scholar; thus, his achievements sparked a new sense of resolve within the disabled community.

Disability Studies aims to interrogate normalcy through a 'social model' lens. The 'social model' was developed by disability activists who realized disability is not a personal problem, it is a socially constructed problem (Cameron, 2014.p. 137). People experience impairments; however, it is society which disables them.

In 1980, the World Health Organization published an *international classification of impairment, disability and handicaps* (ICIDH) (WHO, 1980 in Barnes & Mercer, 2010). This classification described disability as a ‘lack of ability to perform an activity in a manner that is considered *normal* for a human being’ (Barnes & Mercer, 2010, in Cameron, 2014. p. 99). Being an authoritative organization, this classification quickly became the image of disability which established the belief of disability as an individual problem because they deviate from the ‘norm’ (Cameron, 2014.). This classification lead society to view disability as an individual tragedy that needs to be ‘fixed’ in attempt to have “desired able-body”.

Prior to the classification of disability, individuals with impairments were accepted among society and impairment was understood as “inevitable” and “ordinary” therefore, everyone could live and work alongside their family and others within the community (Cameron, 2014. p. 66). In later years, there was a rise in production demands which resulted in building large factories with standardized machines to increase production. As more factories were developed, more machines were created, and standard-shaped, able-bodied workers were needed (Cameron, 2014.p. 66). These factories and machines were designed for ‘able-bodied’ individuals and therefore, individuals with impairments could no longer work alongside everyone else. Seeing this privilege, being able-bodied quickly became the desired way of life and being impaired was a tragedy separating you from society.

This oppression of people with impairments later led to disabled individuals fighting for human rights, citizenship and independent living (Barton, 2010. In Cameron, 2014. p. 37.). These individuals were not being given equal opportunity to work and live as a part of society

because they were viewed as ‘inferior’ and ‘pitiable’ for not fitting the ‘desired norm’, therefore, they lost autonomy of their lives because ‘able-bodied’ people believe they know what is best.

### **Reimagining the Triad of Impairments**

In the chapter “Autism as Culture” by Joseph Straus (in Davis, L. J. (ED). *The Disability Studies Reader*, 4<sup>th</sup> ED. (p. 460-484.). N.Y.: Routledge) the triad of impairments developed from the medical model are critiqued. The medical model views Autism as a personal problem in need of a “cure” however, through this critique, Straus examines Autism as a “function of interactions between people” (pp. 466). Through the adoption of the social model, individuals with ASD are viewed as a culture of people sharing a similar experience.

The Diagnostic and Statistical Manual of Mental Disorders (DSM) contains the medicalized diagnostic criteria for Autism and other “mental illnesses” (Straus, 2013). In the fourth edition of this manual, “Autistic Disorder” is diagnosed by a set of criteria known as the “triad of impairments”. These criteria include: 1) Impairments in social interaction; 2) Impairments in communication; and 3) “restricted, repetitive, and stereotyped patterns of behaviour, interests, and activities” (Straus, 2013). Reflecting on this set of criteria, it becomes evident that through a critical disability studies perspective, each of these “impairments” are exaggerated examples of socially desirable traits many humans admire. I will unpack the triad of impairments as reimagined by Straus (2013).

#### **1) Fixity of Focus**

*“The autistic cognitive and artistic style often involves doing one single thing with great intensity, again and again.”* (Straus, 2013. pp. 468).

Fixity of focus is like a well-known trait associated with ASD first described by Kanner as a “preference for sameness” (Kanner, 1943), most individuals with ASD share the desire for orderliness, repetition and structure. Maintaining a consistent routine and rituals prevents unnecessary confusion and discomfort. Straus explains how this trait allows individuals to do one thing with great intensity; a trait many of us desire to have. In a world of distractions and fast-paced living, we are required to do a substantial amount of multitasking. However, it has been stated that the higher the level of multitasking, the lower the level of accuracy (Adler & Benbunan-Fich, 2012). The more we multitask, the more things are requiring our attention and as a result, nothing is done with great intensity. Thus, Straus explains how “single-mindedness” and “obsession” are desirable traits many people strive for to be successful.

## 2) Local Coherence

*“Unlike those of most people, my thoughts move from video-like, specific images to generalization and concepts. For example, my concept of dogs is inextricably linked to every dog I’ve ever known... the images I visualize are always specific. There is no generic, generalized Great Dane.” (Grandin, 1995. p. 27-28. In Straus, 2013. (Ed.) Autism as Culture. p. 468).*

The reimagined trait defined as “local coherence” is the ability to pay extensive attention to detail. Like the Temple Grandin quote above explains, each detail is perceived as a whole in itself and is not present to serve a greater totality (Straus, 2013). Grandin explains how each dog she sees is stored in her memory however, because she has seen one dog, one time, that information is not generalized to all breeds of dogs.



Often people miss important details because so much time is spent looking at the big picture. If we spent more time looking at each detailed part and stopped generalizing information, we may have a greater outcome when completing tasks.

### 3) Private Meanings

*“In the bus on the way to school the next morning we passed 4 red cars in a row, which meant it was a **good day**...”* (Hadden, 2004. p. 24.)

Lastly, Straus explains a common desirable trait of Autism he refers to as “private meanings”.

Many individuals with ASD use alternative forms of communication that involve various combinations of images, sounds and words. This language is formed from locally coherent associations in which the sound of a word is as pleasurable as the meaning (Straus, 2013).

Therefore, “autistic language” involves personal reasoning and literal, concrete thinking rather than abstract thoughts. Each association has a logical reason and meaning to that individual, an example is given above in the quote from the book *“The Curious Incident of the Dog in the Night-time”* where the main character with ASD and has developed his own private meanings for red cars. Individuals with ASD rely of their desire for privacy and will often ignore social conventions because of their logical associations and private meanings. Therefore, many individuals with ASD do not live life in pursuit of pleasing others. They live their lives the way it makes sense to them. This is a socially desirable trait many people wish they could pursue. Many of us spend most of our lives trying to conform to social normality at the expense of our own values and beliefs.

Through this critique of the medical model of ASD, Straus has urged us to look beyond the diagnosis and understand that ASD is not a personal problem, it is a societal issue. The common understanding that individuals with ASD desire to be alone is solely based on social

interactions. Aloneness is not something one achieves on their own, aloneness is a product of interactions; we do not know what alone is unless we have experienced it from the loss of a connection to another human being. By embracing these remarkable traits associated with ASD, we can further understand these characteristics and realize, they are only considered “abnormal” because they do not conform to societal norms. We can further question our values and beliefs to understand why these social constraints exist.

### **Framework for Emancipatory Research**

In 1997, Mark Priestley proposed a framework for emancipatory research. Emancipatory research is not “to help the researched to understand themselves better, but to develop its own understanding of the lived experiences of these very subjects.” (Oliver, 1992. p. 111). Priestley inquired whether it was possible to conduct disability research by simply placing his skills “at the disposal” of the participants to see how far the process would go being led by the participants (Priestley, 1997. p. 88). This inquiry developed six core principles of emancipatory research. Here, a few key principles will be outlined:

#### *1) The adoption of the social model as a basis of research production*

Through the adoption of the social model as my perspective of disability, I hold the belief of individuals with impairments as people who have been disabled by societal factors. I perceive an impairment as a physiological trait many people experience however, a person only becomes disabled by limitations imposed by their surroundings. Thus, a wheelchair user is only disabled when a public space does not have wheelchair accessible accommodations. Similar, a deaf person is only disabled when people they interact with do not know sign language to communicate.

2) *Surrendering false claims to objectivity through overt political commitment regarding the struggles of individuals with disability for self-emancipation*

To surrender false claims to objectivity I must reject traditional positivist claims which value disconnection between the researcher values and the project. I fully embrace my connection to my project and openly share my reflexive position. Phenomenological orientations use a method known as “bridling”. Phenomenological researchers use bridling to share details about their assumptions, values, and biases. Bridling allows the researcher to adopt an attitude of openness when describing a phenomenon (Singh, A., 2015. In Johnson, C. and Perry, D. (eds), 2015).

3) *The willingness only to undertake research where it will be of some practical benefit to the self-empowerment of individuals with disabilities and/or removal of disabling barriers*

Undertaking this user-led research project means I worked with my participants to encourage self-empowerment. I am offering my research services to the use of my participants for them to share their stories and illuminate the experiences they endure in a typical week. Through sharing these stories, we will work together to raise a greater understanding of living with ASD with a hope of a more adaptive, accessible community.

4) *The transference of control over the research production to ensure full accountability to individuals with disability.*

I tried to transfer control over the research production to my participants to ensure their perspectives are being shared. When describing the phenomena being researched, I left my interview questions short and open to allow the participants space to discuss what they feel is most important.

5) *The ability to give voice to the personal while attempting to collectivise the commonality of disabling barriers and experiences*

People share an experience however, they will always perceive it differently. The experience of living with ASD is shared among many individuals thus, some factors experienced in one person's typical week may be transferred to many others living in similar situations.

6) *The willingness to adopt a variety of methods for data collection and analysis to meet individual needs*

Given the individual needs of my participants, I have taken the time to build rapport with them to be able to adapt to their needs. This principal was significant during the observation stages because being able to adapt my involvement and understanding my observations was based on the individual.

Since this framework was developed, several researchers have attempted to implement personal perspectives and direct reporting by individuals with disability into their research (Obrusnikova & Cavalier, 2011; Pan & Frey, 2006; Stanish et al., 2015). Previous research has used alternative methods of collecting data through photovoice interviews (Obrusnikova & Cavalier, 2011) and written or verbal questionnaires (Pan & Frey, 2006; Stanish et al., 2015). Although each of these studies aimed to implement the personal voice of the participants, all studies were conducted using individuals who were verbally communicative and high-functioning.

Through the adoption of these principles, I aimed to develop my study working with my participants to understand their perspective. To my knowledge, no research has been conducted to identify barriers experienced by transition age youth with autism; therefore, this will address a significant gap within the literature. Identifying perceived barriers within a population that is

often excluded from most research due to the complexity of the disorder and non-traditional forms of communication will contribute to implementing more accessible physical activity programs.

### Chapter 3: The Research Design

“Sometimes you will never know the value of a moment until it becomes a memory”

— Dr. Seuss

#### **Hermeneutic Phenomenology**

Throughout this section, I will be referring to the work of Max Van Manen (1990) to describe the methodological applications of phenomenology. Van Manen (1990) explains phenomenology is understanding how one experiences and makes meaning of a phenomenon. Through phenomenology, we examine the lifeworld as it is being experienced without classification or conceptualization. This perspective will unearth the “what” and “how” of a phenomenon rather than classifying the experiences to develop a theory of “why”.

The philosophy and methodology of phenomenology has expanded throughout the years and multiple ‘branches’ have been developed. For my study, I will be implementing ‘hermeneutic phenomenology’ which is better understood as the ‘interpretation’ of lived experiences (Creswell, 2013). The grandfather of hermeneutic phenomenology, Heidegger explains “the meaning of a phenomenological description as a method lies in interpretation... The phenomenology... is a hermeneutic in the primordial signification of this word, where it designates this business of interpreting” (1962, in Van Manen, 1990.pp. 25). The philosophy of hermeneutics believes description of an experience cannot be separated from interpretation because as human beings with consciousness, we strive to understand and make meaning of interactions within the lifeworld. In other words, humans cannot separate their consciousness from their bodies. human consciousness is embodied consciousness. I am not an ‘insider’ therefore, I will be interpreting and creating robust descriptions of the participants’ lived

experiences to understand the world from their perspective. For this reason, I have chosen Hermeneutic Phenomenology as my methodological perspective.

### **Consent and Procedure**

This study received Ethical clearance from Brock University Research Ethics Board (File # 16-315 Please see Appendix A for Certificate of Ethical Clearance) prior to participant recruitment. Once Ethical clearance was received, potential caregiver participants were contacted via e-mail (see appendix B) with a letter of invitation (see appendix C). Once the potential participants e-mailed back stating they were interested in participating in the study, I then sent them an e-mail requesting a date and time they were available to meet to review and sign the informed consent. Due to the availability of each participant, I was asked to meet them in their homes where I met with them, explained the study in detail, and discussed what would be asked of them and their teen to participate in the study. I then reviewed the caregiver informed consent with them and obtained their signature (see appendix D) then reviewed the informed consent for their teen and had the caregiver provide consent (see appendix E) due to ethical considerations. All participants were later asked if they would like to pick their pseudonym, however, all participants declined and asked the researcher to pick for them (See table 1 below).

Once informed consent was obtained, the caregivers contacted programs their teen attended and connected me to them via e-mail to arrange for observations. All programs approached were more than happy to have me come and observe. When arriving for my first observation at each program, I met with either the program manager, coordinator or day staff lead and had them sign an organization informed consent (see appendix F).

Table 1.

*Participant's and their corresponding caregivers*

<b>Youth Participant</b>	<b>Demographics</b>	<b>Caregiver(s) Participant</b>
<b>Keira</b>	19-28 Female	Kyla
<b>Chester</b>	19-28 Male	Charlotte
<b>Adam</b>	19-28 Male	Anna and Anthony

### **Participant Recruitment**

For my study, I recruited participants through purposeful criteria and intense case sampling strategies. Purposeful sampling is used in qualitative research to recruit participants who experience the central phenomenon of the study (Creswell, 2013. p. 156). Specifically, criterion sampling is used in my study because all participants involved meet specific criteria, which is being of transition age, diagnosed with ASD and typically requiring 1:1 support or greater as well as their caregivers. These criteria are purposeful because this specific group is marginalized and excluded from most research and together, they can share their experiences of the phenomenon of living with ASD. The participants invited to participate were recruited through intense case sampling because these participants are “information- rich cases that manifest the phenomenon intensely” (Patton, 2002. p. 243). Similarly, I also used convenience sampling because I work with these individuals at an adaptive physical activity program. Although convenience sampling has been said to limit information and credibility (Creswell, 2013. p. 158), for my study, I do not believe this is the case. Gaining access to a ‘vulnerable’ population can be a very difficult, tedious task, therefore, already having access and an established rapport with the parents/ caregivers was crucial for my study.



## Data Collection

Following a hermeneutic phenomenological orientation, the two main sources of data collection for my study were observations and interviews. I first conducted observations with the youth participants in different community program settings. These observations were an attempt to see their experiences from their perspective since these individuals do not use words to communicate. I entered each observation watching for any gestures, movement, sounds and expressions that would give me insight into their experience and feelings in that setting.

At the time of the observations, Keira was only attending one day program at the time therefore I conducted the observations all at the one program. However, I attended on 3 different days of the week (Monday, Tuesday and Thursday) to see what activities they participate in on different days. In comparison, Chester was participating in two different programs at the time of the observations therefore I was able to observe him twice at an adaptive martial arts class which he attends two nights a week and once at a community facility with his respite worker. Similarly, Adam also was enrolled in two different programs, a day respite and a summer camp. I was able to observe Adam twice in the day respite program; once at the facility and the other time at a community pool.

While observing each participant in their programs, I tried to sit off to the side and out of the business of the activity however, at some points I would engage with the participants. For my first couple observations I tried using an observation note taking sheet that I created (see appendix H). However, I quickly realized that the sheet was making it difficult for me to simply observe what was happening because I was caught up in looking for specific *things*. I then switched to lined paper where I made bulleted notes of what was happening around me. I observed the environment, movement, body language, interactions, and engagement.

Once all the observations were complete, I began interviews with the caregivers, who in this study, were also the parents of each youth participant. Hermeneutic Phenomenology suggests using multiple, conversation style interviews for the researcher and participants to discuss the meaning of an experience. Using interviews is often preferred over participants' writing because phenomenology aims to understand an experience as it is lived and writing often facilitates a more reflective approach (Van Manen, 1990. pp. 66) while interviewing can often allow the informant to 're-live' the experience in a more immediate way. In line with my methodological orientation, I believe it is impossible to be fully prepared for an interview, leaving space for silence, or using simple prompts can help the participants organize their thoughts and elaborate on their stories. Each person may perceive the same experience differently, thus, having an overly structured interview guide can hinder detailed information about *their* story and result in many 'missed opportunities' for the researcher.

Being a novice researcher, I understand I need to use some form of an interview guide, for this reason, I used 'semi-structured' interviews for my study. My guide consists of a few questions then leaves space for silence and follow up as suggested for a phenomenological study (see appendix G). Each interview was scheduled for 60 minutes however, they varied in length depending on the participants. I gave them time to collect their thoughts and elaborate on their story without being rushed through a series of artificially formalized questions. I completed one semi-structured interview with each caregiver using my interview guide (appendix G). After the initial interviews were complete, there was no need for a follow up. All interviews were recorded using an audio recording device and were transcribed verbatim. Once each interview was transcribed, I e-mailed a copy of the transcription to the caregivers and asked them to review it to give them a chance to change any information shared. All caregivers responded with no changes.

Another form of data collection I attempted to use was a researcher journal and memo notes. I planned to collect memo notes during each interview and transcription to identify my own values, beliefs and possible presumptions regarding the experiences discussed (Glesne, 2016). I did keep notes when I felt necessary, however, I was unable to keep memo notes during the interviews because I was focused on following the conversation. I did keep journal notes where I periodically collected my opinions, presumptions, challenges, and successes throughout my research journey. I used this mode of collection as a trustworthiness strategy to identify my reflexivity and positionality throughout the process.

### **Data Analysis**

During the initial phases of my project, I had to obtain approval from the Ethics board before beginning my data collection. Upon receiving my Ethics Board's feedback, my supervisor and I felt it was an appropriate data set that should be analyzed and included in my project; therefore, analysis began with Ethics. Once I received approval and I knew the clarifications and revisions section was complete, I printed both rounds of feedback and read the document highlighting information that stood out to me. I then reread the document and created "meaning units" from the highlighted notes, including but not limited to: "questioning ability", "capacity", and "professional/expertise". After I had my meaning units, I decided to take quotes from the feedback and plug them into a "word cloud generator" (see appendix I). Looking at the word cloud my themes became much more evident and I was able to easily group my meaning units into the themes I generated.

## Thematic Analysis

Hermeneutic phenomenology differentiates between two forms of interpretation: revealing what the thing itself is or confronting a thing that is an interpretation already such as a painting (Van Manen, 1990. pp. 26). I focused on the first form of interpretation to unearth elements of the experiences as they are told, to do this I used a thematic analysis.

Thematic analysis is a common method used in hermeneutic phenomenology. Van Manen (1990) explains a ‘theme’ is simply a reoccurring element within a text. Therefore, a theme analysis is the search for and extraction of thematic elements *that are embodied* in the *meaning* of the text. (pp. 78; original words italicized) Through thematic analysis, I interpreted the meaning of the experience that is being described, this process enabled me to freely explore the essence of the phenomena. Van Manen refers to this process of identifying phenomenological themes as ‘*structures of experience*’ because as a researcher conducting a phenomenological study, I aimed to understand the lived experience being shared. Therefore, my themes are simply fragmented parts that together structure the whole.

Hermeneutic phenomenology has a dynamic process for thematic analysis which requires attentive reading, rereading, writing, and rewriting. To follow this process, Van Manen proposes a sequence which includes: 1) reading to get a sense of the ‘whole’, 2) selective reading for salience, and 3) detailed rereading. Wholistically, I read the transcripts for salience within the whole text; selectively, I revisited the text and read for prominent, significant statements, or phrases which I felt were revealing about the experience being shared; and in detail, I attentively read line-by-line to identify the ‘meaning units’ of each sentence and question what each sentence *reveals about the experience?* (1990. pp. 93). Once I had created my “meaning units”, I cut them out line by line and began sorting them into themes which I then connected by drawing

out a thought map (see appendix J). The recursive reading process and visual layout of themes allowed me to get a sense of various patterns as well as salience, and these patterns were instrumental in providing a robust description of the barriers experienced by the three informants.

### **Collaborative Analysis**

After I have developed themes and patterns from the data, my supervisor, Dr. Maureen Connolly, and myself revisited the themes for further analysis. Through this process, we *re-examined, reinterpreted, added, and/or omitted* to reformulate the preliminary themes (Van Manen, 1990. pp. 100). As the principal investigator, I conducted the observations, interviews and transcribing making it impossible to do a ‘true’ first read of the whole. Therefore, incorporating collaborative analysis with an investigator who was not present during these preliminary phases allowed the collaborator to connect with the text differently from myself and ensure I am not pulling out patterns that I am consciously *looking for*.

### **Existential Analysis**

The aim of this study is to understand the meaning of the lived experiences of transition age youth with ASD. To understand these experiences, I must explore their interactions within different lifeworlds. As human beings, we are dynamic and act purposefully within the world to make sense of each experience as it is experienced; in doing so, we *inhabit different lifeworlds* throughout the day (Van Manen, 1990). As we interchange between our lifeworlds, we interact in different spaces, times, relationships, and embodiment. Four fundamental lifeworld ‘themes’ have been developed, known as ‘existential’. These existential themes are created as guides for reflection for understanding lived experiences, these include: lived body, lived space, lived time, and lived human relation (Van Manen, 1990); these themes will be briefly discussed.

*Lived body* refers to the phenomenological concept that we present ourselves within the world as bodies. In human interactions, our bodies are the first identifiable component of us, our bodies make us a physical being within the world. How our bodies interact with our lifeworlds reveals and conceals information about ourselves (Van Manen, 1990). *Lived space* is known as “*felt space*”. Our *felt space* goes beyond physical space such as distance, or size; it is the various spaces we inhabit which effect how we feel. When our lived body moves into new spaces and areas, feelings and sensations are elicited because of the space we are in (Van Manen, 1990). If we are lost in a forest and it becomes dark outside, our physical space elicits a response of fear within our *felt space*. *Lived time*, like *lived space*, is subjective. Van Manen explains “lived time is the time that appears to speed up when we enjoy ourselves, and slow down when we feel bored...” (1990, pp. 104). *Lived time* is our temporal way of existing in the world, past experiences are carried with us into our future experiences and continue to change as our temporality changes. Lastly, *lived relation* is our interactions and relationship with others. As humans constantly in search of meaning, we search for social relationships to guide our purpose in life (Van Manen, 1990). These lifeworld existentials allowed me to construct descriptions of the barriers experienced by the participants that honors the fullness of the participants’ personhood (that is, the body, space, time and relational dimensions of their experiences).

### **Trustworthiness: Prolonged Engagement and Ethical Considerations**

Being connected to the participants, as discussed throughout this paper, I realize I have presumptions and opinions regarding the information shared, or my own expectations of what I observed. Due to my personal connection to this research study, I have attempted to remain transparent regarding my thoughts, and feelings during this process. There were numerous situations where I acknowledge my experiences working in the field contradicted what I

observed however, I continually had to put my expectations and experiences aside to simply observe and listen to the stories I was being told.

Throughout this process I found myself conflicted with various ethical considerations. There were times where I was told stories that did not exactly pertain to my study but were valuable stories I felt that should be shared. Similarly, when beginning observations, I entered the field to simply observe what the participant does and does not do while in the programs. However, there were times I made note of interactions or activities that I was not initially there to observe because they were hard to ignore and provide significant context to the stories being shared. For this reason, I have included many of my own thoughts and experiences throughout this process and chose to share these deep, meaningful stories I was given to share.

Lastly, a significant ethical consideration I was challenged with throughout the study was with regards to confidentiality. When working with small, intense sampling confidentiality was an ongoing concern which is a main reason why I have left descriptions of the participants out of this study and tried to keep all information regarding programs and staff as neutral as possible. These were all valuable stories that contribute significantly to the gap in research, however sharing these stories had to be done carefully with removing some details that may have been easily traced back to the participants.

## Chapter 4: Findings

Following analysis several themes emerged from the data collected. The findings have been separated based on the form of data collection used and then further broken down into the individual themes. First, a “week in the life” for each participant is described and summarized. Then the findings from the Ethic’s Board feedback is presented by two themes, “researcher role(s)” and “the unquestioned starting point”. Next, the interview findings are highlighted, and the emerging themes are: “community vs. crowd”, the “professionals”, and “the out of control body”. The observational findings are then shared. Through observation the three themes that arose are: “Individualized Programming”, “who’s working today?” and “programming supports and insights”. Lastly, using phenomenological analysis, the findings have been further analysed using lifeworld existentials to give a greater description of the complexity of these mundane activities.

### **Findings: A Week in the Life**

“A week in the life” has been created for each participant from information shared in the interviews with the caregivers. Each glimpse into their typical weeks shows what kind of supports they receive, how often they receive them and how much of their time is spent in community programs.

#### **Adam**

Adam is a highly anxious, persistent individual who loves to have everyone’s full attention. Adam often expresses his anxiety through laughter or pinching and scratching. As well, if Adam does not want to participate in a task or activity, or does not find it purposeful, he can be very persistent in standing his ground and not conforming to the task simply because he has been asked to do so. During the interviews, Adam’s caregivers discussed his likes and dislikes,



specifically how “*he is very motivated by the wind*” (Anna). When the weather is warm, sunny and windy, he is completely content to spend hours sitting outside enjoying the weather.

However, they also explained how because of this admiration for warm, windy weather, when there are days he cannot be outside, he can become quite destructive if left disengaged and bored.

At the time of the interviews, a detailed break down of Adam’s week is:

Monday- Friday: School and worker days

- 6:30 am: PSW arrives: gets him up, showered, dressed and downstairs
  - Mom makes breakfast and lunch and packs his bags
- 7:30 am: School bus arrives, Adam gets on out front of house
  - Goes to school. Anna: “I don’t know exactly what goes on at school”
- 2:00 pm: School bus drops him off at home, mom meets him at school bus to get him off
- 2:30-4:30 pm: worker comes, and they go out for a drive or walk
  - Weather greatly impacts his schedule. If it is warm and windy outside, Adam will go straight outside after school for most of the evening. If the weather is bad and he is not going out with a worker, he will become “destructive” at home.
- Saturday: go swimming with a worker, go to the Y to “play ball” or go to SNAP
- No weekly written or visual schedules used. “first, then” strategy used for transition and preparation to next task/activity

After reviewing the information shared above, I took the detailed week and put it into a table to give a better visual representation of the week:

Table 2.

*A Week in the Life: Adam*

	<b>Mon</b>	<b>Tues</b>	<b>Wed</b>	<b>Thurs</b>	<b>Fri</b>	<b>Sat</b>	<b>Sun</b>
<b>Morning (5am-12pm)</b>	Get ready/ bus/ school	Get ready/ bus/ school	Get ready/ bus/ school	Get ready /bus/ school	Get ready/ bus/ school	Home	Home
<b>Afternoon (12pm-5pm)</b>	School/ bus/ home/ outside or	School/ bus/ home/ outside or	School/ bus/ home/ outside or	School/ bus/ home/ outside or worker*	School/ bus/ home/ outside or	SNAP or worker (swim/ ball/ walk/	Home

	worker* (walk or drive)	worker* (walk or drive)	worker* (walk or drive)	(walk or drive)	worker* (walk or drive)	drive) or outside at home	
<b>Evening (5pm- bed)</b>	Home	Home	Home	Home	Home	Home	Home

\* Out with a worker two afternoon's a week however, days were not specified.

As seen above, Monday to Friday consisted of attending school during the day until 2pm. Once he gets home from school, two days a week he has a worker who comes and picks him up and they go for a drive, walk, or to the local YMCA to play ball. The other three days a week, Adam comes home from school and his mother takes him out for a drive or a walk. During the interview, Anna and Anthony explained how Adam going out with a worker two or three days a week was a new change in his schedule because they had recently received passport funding. Prior to receiving this funding, Adam's mother was unable to work because she would be the one to take him out every night after school to keep him occupied. At the time of the interview, Adam was not attending any programs except on Saturday's. However, at the time of the observations, Adam was attending a "day respite" as well as a summer camp. During the interviews, Anna and Anthony also expressed the challenges they have trying to find programs that are meaningful and accommodating to Adam's needs.

### **Chester**

Chester is a very compliant and "go with the flow" kind of person who is willing to participate in just about any task or activity. Chester can become quite anxious when he is uncertain about what is being asked or left with unplanned time not knowing what is coming next. When Chester becomes anxious he expresses himself through explosive movements where he will rapidly move

his body away from the space or individual causing him anxiety while waving his arms and making vocal sounds.

At the time of the interviews, Chester's typical week was as follows:

Monday-Friday: School and Program days

- Mom gets him up and helps him get ready for school
- Mom drives him to school and then goes to work while he's at school
- He then comes home, has a snack and plays on the computer

After school programs:

- Mon: Martial Arts
- Tues: Out with respite worker
- Wed: Martial Arts
- Thurs: (in between programs at time of interview)
- Fri: Mom tries to keep this night "empty"
- Sat: SNAP or activity with Mom
- If the weather is nice, they try and keep their weekends free to go hiking, biking, or for walks
- No written or visual weekly schedule. Verbal reminders given before going to activity.

From the detailed description of the typical week, I created a visual representation, see table 3.

Table 3.

*A Week in the Life: Chester*

	<b>Mon</b>	<b>Tues</b>	<b>Wed</b>	<b>Thurs</b>	<b>Fri</b>	<b>Sat</b>	<b>Sun</b>
<b>Morning (5am-12pm)</b>	Get ready/ school	Get ready/ school	Get ready/ school	Get ready/ school*	Get ready/ school	Home	Home

<b>Afternoon (12pm-5pm)</b>	School/ home/ “destress”/ computer	School/ home/ “destress”/ computer	School/ home/ “destress”/ computer	School*/ home/ “destress”/ computer	School/ home/ “destress”/ computer	SNAP or activity with Mom	Home
<b>Evening (5pm-bed)</b>	Martial Arts	Worker	Martial Arts	Transitioning between programs (Recreation program to Physical Activity)	Home	Home	Home

\* Transitioning out of school into day program

As seen above, Chester’s typical week consists of him attending school Monday-Friday, and programs almost every evening. During the interview, Charlotte explained that Chester was beginning to transition out of school slowly and was going to be starting at a new day program on Thursdays. Each day when Chester gets home from school, he plays on his computer before getting ready to go to his evening program. Each night of the week, Chester attends a different program or activity which his mom drives him to and picks him up from. On Mondays and Wednesdays Chester would attend an adaptive martial arts class where he was supported 1:1. On Tuesdays, Chester would go out with his worker and they would participate in activities such as swimming or going to the trampoline park. At the time of the interview, Thursday evenings Chester was transitioning between a recreation program and an adaptive physical activity program. On Friday nights, Charlotte explained they try to keep them unscheduled to just relax because after a busy week, “[they] all need a break”. She also explained how when the weather is nice, they try and keep their weekends open to do activities together such as, hiking, and biking.

## Keira

Keira, like Chester, is a “go with the flow” kind of person. She is quite social and enjoys being out in the community and with other people. Keira is impatient and does not like to spend time waiting or disengaged because she becomes bored and will often wander around to keep herself busy and occupied.

In the interview, Kyla gave a very detailed break down of Keira’s ‘typical week’:

Monday-Thursday: Day program

- Between 5-6 am: Keira gets up
  - Mom changes her, and her bedding then does laundry while Keira goes down to her computer
- Mom makes breakfast for Keira and then for herself
- Keira has a bath before they leave
- Leave the house at 8:30am
- Mom drops of Keira at day program (Mon-Thurs) and mom goes to work
- Mom picks her up at day program
- As soon as they get home, Keira has a bath
- Mom makes dinner while she’s in the tub
- Keira eats dinner, then goes upstairs and has a rest
- After her rest she goes downstairs and plays on the computer and watches movies then goes to bed
- Fridays: Keira gets up and starts taking out all her mom’s cleaning supplies then mom starts cleaning
- 10am: they go and pick up grandma and go shopping until 3pm
  - Keira usually gets a toy while they are out shopping on Fridays
- Saturdays: depends on whether they are doing house renovations, but they usually go shopping
  - Visit the other grandma
  - Just trying to keep Keira busy because “she gets bored in the house”

- Or SNAP
- Some weekends they go out and do family activities such as trivia night or to concerts
- No weekly written or visual schedule. The schedule remains the same most weeks, “*it’s just so ingrained in all of us*” (Mom).

I extracted the salient tasks and activities and created a visual representation of Keira’s typical week:

Table 4.

*A Week in the Life: Keira*

	<b>Mon</b>	<b>Tues</b>	<b>Wed</b>	<b>Thurs</b>	<b>Fri</b>	<b>Sat</b>	<b>Sun</b>
<b>Morning (5am-12pm)</b>	Get ready/ bath/ day program	Get ready/ bath/ day program	Get ready/ bath/ day program	Get ready/ bath/ day program	Get ready/ take out cleaning supplies/ bath/ Grandma & shopping	Home	Home
<b>Afternoon (12pm-5pm)</b>	Day program/ home/ bath	Day program/ home/ bath	Day program/ home/ bath	Day program/ home/ bath	Shopping/ home/ bath	Visit Grandma or SNAP or Shopping	Home
<b>Evening (5pm-bed)</b>	Dinner/ rest/ computer	Dinner/ rest/ computer	Dinner/ rest/ computer	Dinner/ rest/ computer	Home	Home	Home

As seen above, her typical week consists of attending a recreational day program Monday-Thursday since she is no longer in school. Each morning, Keira gets up, has her breakfast and a bath before her mom, Kyla, drives her to the day program. At the day program, Keira is in a group with about five other participants and one or two staff. At the program they will often spend time at the facility doing crafts, using the pool or going out into the community. After the day program, Kyla picks Keira up and she comes home and spends the rest of her evening relaxing by having a bath, listening to music, playing on the computer and watching TV. On Fridays and some Saturdays, if Keira does not have SNAP, her, her mom and sometimes grandmother, spend the day shopping. Her mom explained in the interview that Keira is well

known, and well liked at all the stores they go to because they have been regular customers for a while. She further discussed that they always try and keep her busy on weekends by shopping, going to trivia nights or other community activities as a family because “*she gets bored being in the house*” (Kyla).

Each person’s typical week gave valuable insights into their daily life. After reviewing each person’s typical week, the salient information was taken, and a summary chart was created.

Table 5.

*Participant ‘Week in the Life’ Summary*

<b>Name</b>	<b>Programs and Activities</b>	<b>Personality and Supports</b>
<b>Adam</b>	<ul style="list-style-type: none"> <li>- Day program/ respite</li> <li>- Worker (swimming, ball, walking, drives)</li> <li>- Summer camp</li> <li>- Mom (drives and walking)</li> </ul>	<ul style="list-style-type: none"> <li>- Anxious</li> <li>- Persistent</li> <li>- 1:1 support</li> </ul>
<b>Chester</b>	<ul style="list-style-type: none"> <li>- Martial Arts</li> <li>- Worker (swimming, trampoline park, hiking)</li> <li>- Recreation program</li> <li>- Community engagement program</li> <li>- Mom (biking, hiking, grocery shopping)</li> </ul>	<ul style="list-style-type: none"> <li>- Wanders/ “Bolts”</li> <li>- Anxious</li> <li>- Compliant</li> <li>- 1:1 support</li> </ul>
<b>Keira</b>	<ul style="list-style-type: none"> <li>- Day program</li> <li>- Mom and Dad (shopping, trivia night, etc.)</li> </ul>	<ul style="list-style-type: none"> <li>- Wanders</li> <li>- Impatient</li> <li>- 5:1 support</li> </ul>

Upon the creation of the chart, various patterns and differences became evident when comparing each individual week. Firstly, it was noted how many more programs and activities Chester was participating in compared to the other two participants. While reviewing these typical weeks, I could not help but wonder if this is because of Chester’s easy-going personality that many programs are able to meet his needs better than other people who may not be so easy going and

compliant. Another pattern that arose from these typical weeks was the involvement of the caregivers. For all the participants, the caregivers are very engaged in their lives however, it was evident that the less programs they had access to, the more intensely involved the caregivers had to be to keep them occupied and engaged for not only enjoyment but their safety and dignity. All three participants do not enjoy time left their unplanned or disengaged and often this boredom would result in anxiety or destructive actions. Lastly, seeing how much of their time is spent in programs, I began to question just how of the much time spent were they meaningfully engaged in the activities and not just managed.

### **Findings Ethics: “Is it unethical to be ethical?”**

I would like to begin this section by clearly stating my reflexive position. I do acknowledge that the Research Ethics Board is doing their job by flagging any potential ethical concerns they see. I do understand why I received the feedback I did because they follow set criteria. It is not my intention to attack our research ethics board. In contrast, I am analyzing this content to bring attention to the inadvertent exclusionary practices that follow from a lack of exposure to high needs populations. More research needs to be conducted in this area, especially given the albeit unintended oppressive practices implied by several of these policies and procedures.

### **Theme: Researcher Role(s)**

After putting my ethics feedback into a word cloud (appendix I), it became evident that the biggest controversy identified was regarding my role. The Research Ethics Board (REB) emphasized their concern regarding conflict of interest due to my relationship with potential participants.

*“Note that you cannot simply assume that the potential participant who is your client will understand and be able to differentiate your role as researcher from your role as a respite*



*worker. Since this potential participant has a pre-existing relationship with you, certain factors may diminish their ability to exercise autonomy, such as inadequate information or understanding for deliberation, or lack of freedom to act due to controlling influences or coercion”*

*“...How might you facilitate comprehension? Or **consider excluding this participant**, due to a conflict of interest between your role as a researcher and respite worker...”*

Previous literature working with individuals who experience profound intellectual disabilities and multiple disabilities (PIMD) explained “that it is actually unethical to exclude persons with PIMD from research that could provide insights about their subjective experiences, and about how to promote their well-being” (Tuffrey, Wijne, Bernal, and Hollins, 2008, p. 188 in Mietola, Miettinen, & Vehmas, 2017, pg. 264)

I also understand that the REB must ask questions (outlined below) regarding how I will be able to adapt to the participants’ needs and/or understand when they are becoming uncomfortable with my role as a researcher. However, recent research with high needs populations indicates that building long term relationships and rapport building are critical elements in authentic valid research with high need populations (Mietola, Miettinen, & Vehmas, 2017).

*“... given the greater amount of support your participants require, do you anticipate needing any professional skills or experience with this population, not only to manage their basic needs but also to conduct the interview effectively?”*

*“How might the researchers handle a situation where a youth participant becomes overly stressed or agitated with the task?”*

*“...How will you gauge whether a youth participant wishes to continue with the interview? Will any non-verbal communication need to be considered for this group?”*

**Theme: Unquestioned starting point**

Given that the REB has criteria to follow and may or may not have much experience with or understanding of working with people who experience Autism, a lot of the feedback began with an unquestioned starting point regarding the participants' abilities and comprehension.

*"...How might you facilitate comprehension? Or consider excluding this participant, due to a conflict of interest between your role as a researcher and respite worker..."*

*"Elaborate on whether the participants you have in mind have any cognitive limitations that could impact their ability to give consent/assent? This is unclear in your application because you state that participants have the capacity to delineate your role of a researcher from that of a Respite worker. Also, you suggest that participants will know the difference between participating in the research and participating in SNAP. Finally, you state that the majority of the Saturday SNAP participants have a strong understanding for receptive communications but have challenged with expressive communication."*

The quotes stated above show how the dominant perspective of disability is filled with preconceived assumptions and structural discrimination. Our societal structure is constructed through interpersonal relationships which influence power and opportunity (Thompson, 2010 in Cameron, 2014.).

## Interview Findings

### **Theme: Community vs. Crowds**

Throughout the interview process the caregivers shared their perception of their *child's* preferences and experiences. Multiple caregivers shared stories of times they felt their *child* was part of the community. They expressed their gratitude when community members remember them and acknowledge them.

*Charlotte: "umm.. lots of times [laugh] we get "Hey [son]!" and I don't know who that person is .. and .. and I get oh I work with [son] here, or I see him at school .. and actually its even happening now at the grocery store when we go to Sobeys.. there's quite often kids working there.. who know [son] through school.. cause he's so much older than the kids because he stays longer... so like the grade 12 students ...ya and you're right.. and say hi to him.. interact with him.. its really nice"*

*Kyla: "umm.. Michaels, Superstore, Wal Mart.. they know us.. they know us very well .. to the point that if I go while she's at Respite, they ask where she is.. [R: Do you like that they are so..] ...absolutely because then they know that K is part of the community right ?"*

*Kyla: "it didn't matter what she did, she was always welcomed in that store"*

*Charolette: "I think just the recognition that people recognize him... and say hi to him.. interact with him.. its really nice"*

These above quotes are examples of being part of the community, they emphasize how important these mundane, taken-for-granted experiences are to these families and their adult children.

There is a great divide between being acknowledged as a member of the community, and being seen by other people, rather than being stared at, alienated and feeling like they do not belong in a crowd. Reflecting on my own experiences as a support worker in the field, I can recall feeling

the difference between community and crowd when I am supporting someone in the community. There are many places I am comfortable going because the staff and other community members are welcoming, would greet us and even ask where we were if we were away for a week. In comparison, there were many other places where as soon as we would enter the facility, all eyes were on us. Sometimes these stares were out of interest and other times it was out of judgement and concern. Understanding the significant difference between being a part of the community vs being in a crowd is why many people feel more comfortable in programs and services with other neuro-diverse individuals rather than in community facilities where the majority are neurotypical, able-bodied people.

*Anna and Anthony: "I think.. I think he prefers when he's with other.. other people with disabilities"... "yep, that's where he seems he's more comfortable with somebody with similar needs... its like "I can relax, I can be myself and this person's having fun"*

Here the caregivers explain how it was noticeable how much more relaxed their child was in programs with other neuro-diverse peers. In comparison, caregivers also explained that although their family member likes to be a part of the community, and to socialize, they also become very uncomfortable in crowds. For the sake of this research project, I discerned that 'crowds' are not necessarily based on the physical space of being in a crowd but also the felt space which includes being stared at or alienated.

*Anna: "He doesn't like crowds or stuff like that... but he loves going out.. he wants to be with people"*

*Kyla: "you know what?.. large crowds are not [name]'s thing.. she gets very, very anxious over that"*

*Anna: “He’s very social... He doesn’t like crowds or stuff like that”*

*Kyla: “We’ve had so many stares...”*

These quotes reiterate what was previously mentioned regarding the concept of being seen and being stared at. These participants are receptive to their environments and even if it is not the physical space they feel in a crowd, it may also be the felt space they experience when in a crowd where they are often stared at and alienated as soon as they enter the space.

**Theme: The “Professionals”**

Interviews with caregivers took a bit of a turn and many of them wanted to discuss experiences with program staff or professionals in the community. Some caregivers discussed the challenges of new staff in programs and questioning the quality of training they receive.

*PARTICIPANT: “He was in the [program] and they almost dropped him because.. he couldn’t put a hat on his head... he was too Autistic”*

*PARTICIPANT: “And sometimes the therapists back then, there were some excellent ones but as the program developed and they brought more and more trainee’s in.. they would have two weeks of training sometimes..”*

Here parents are expressing their concern for the competence of the professionals. On a very real level, these parents know that their kids require more care and expertise than a lot of professionals are trained to offer leaving them always hoping and continuously disappointed by the supports they receive.

*PARTICIPANT: “and afterwards we sort of.. we sorta looked at it and we went.. they put basically all the responsibility on the disabled child instead of on the worker...”*

*PARTICIPANT: “They were wonderful.. so you’ve got a kid [worker], that can handle this who.. you know, I felt badly when she got scratched but they could handle it. They understood what*

*they were dealing with and yet you've got a special facility here, that you're paying for and \*they're flipping out on you because your son scratched them.. and I know they must have kept forcing him to do something for him to lash out.. you need to back up, you need to be trained to back up and say "Okay I understand your upset".. it became .. and he is really perceptive, he knows okay you don't like me. You know? He's not stupid.. and I think a lot of it was that he was not comfortable, he did not feel safe and.. and.. obviously uhh.. he.. not that he was unsafe but that he was not wanted there because of their response to the situation"*

Above the caregivers express their disappointment regarding the lack of support their child received from facilities that are supposed to specialize in adaptive programming and support for people with various needs. Similarly, one family discussed experiences with lack of training and awareness among community professionals. They shared two stories, both where the staff/professional clearly did not have the training and awareness; however, each had a different outcome.

*PARTICIPANT: "The security at the parliament building were... insensitive"*

*"They were so.. out to lunch. They wanted him to get out of his wheelchair so they could search him.. it was incredible. It was like "what are you talking about?" they put him through hell.. it was awful... even just the security themselves had no idea of the disabilities they were dealing with.. and wanting him to stand up out of the wheelchair to start with.. and searching him then he was by himself.. anyway it was.. he was sort of by himself for a while.. then he wanted to put him through the metal detector.."*

*PARTICIPANT: "I know he was much younger but when we went to [a resort], the.. the airline was phenomenal as far as pre-boarding and pureeing all his food... the resort which has.. this is in the [tropical country] they have zero experience right... so people who have no experience.. all that hotel had experience with was hospitality.. so if a guest needed some special thing.."*

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\* Some quotes were not connected to pseudonyms to protect confidentiality.

*they'd do it. So when someone who should have that as part of their daily routine doesn't get that..."*

These stories show how crucial it is for professionals to focus on adapting and meeting the needs of the participant/customer/community member. In the top example, you have security guards at the parliament building who should be trained to adapt to many different circumstances, but they showed no understanding of the situation. In comparison, there is the resort staff in a tropical country whose job is to keep their customers happy and would do whatever was needed to ensure they enjoyed their visit.

**Theme: *The "Out of Control" Body***

During the interviews I asked each caregiver about negative experiences they may have had in the community. After I began analysis, it became evident that the negative experiences shared often related back to the individual experiencing Autism and this implicit idea of the "out of control" body.

*Anna: "the other um.. real challenge is the fact that even though we did years and years of toilet training... he's incontinent... hes got some stomach issues... it's a real social barrier that's for sure"*

Their loved one being incontinent was a significant social barrier for this family. This may be because they are concerned about his dignity if he needs assistance in public or because of the lack of accessible, family washrooms available. There have been many occasions where I am supporting a person of the opposite sex and I am stuck because there are no "family" washrooms around and therefore I either must bring them into the female washroom, or I am going with them into the male washroom. Either situation is uncomfortable for them and results in stares from community members making toileting into a much greater situation than it needs to be,

compromising both their privacy and dignity. This is a situation where we cannot change how their body functions and therefore, we must adapt to their needs, as seen in the quotes below.

*Charolette: “he has to go to the sleep dentist.. so.. its stressful on him... he has a lot of sensory with his mouth...”*

*Charolette: “umm.. well we don’t typically get into a situation where we are in a restaurant because he wont eat.. he’s just so limited about what he eats...”*

*Anna: “because he doesn’t like the sound but all his food is pureed..”*

These quotes all highlight the challenge of going to community facilities because of things they cannot control. The challenge with going to the dentist is because of a significant oral sensitivity like the food preferences and limitations. Similarly, the sound of the blender may be a painful sound to the participant which is challenging when he needs pureed food and restaurants do not offer to puree your food for you.

*Anna: “... also a significant change in his life was probably about grade 5 or 6, he had pneumonia and after that he stopped walking up or down stairs... we thought maybe there is a vestibular problem or depth perception or.. ya its very uh.. anxiety provoking for him...”*

As well, the inability to use the stairs may be a sensory challenge, a vestibular issue or a fear. Whatever it is that is causing this inability, the lack of ramps or the placement of the ramps at community facilities creates a challenge for them to participate in community activities.

*Charolette: “...if we have to go to the mall...we don’t go there a lot and theres not a lot there that draws his attention so.. anything that requires him to have to wait... um.. grocery store again... because its somewhere we frequent a lot so if we are waiting in line he may grab something from somebody’s cart... you know... people don’t take kindly to that [laugh] but I think they maybe don’t realize right away what the situation is...”*



Situations which require people to wait can be quite anxiety provoking for the individual. As a support worker, I must strategically plan out arriving and leaving facilities to avoid waiting at all costs. A few people I have supported become quite upset and anxious when standing in a long line or waiting for something to begin. I am unsure if it is the uncertainty of when the wait will be over, or the excitement of wanting the activity to begin or finish and there is this obstacle in the way.

These quotes expose the “cultural expectation of disabled persons and assures that normalcy maintains its status as a dominant but taken-for-granted phenomenon” (Titchkosky, 2003. Pp. 76 in Cameron, 2014. Pp. 108). These daily embodied experiences interrupt and challenge normalcy, in addition to making normalcy’s unquestioned standards visible, and as a result make other people in the community uncomfortable. Since one of the unwritten rules of normalcy is that neurotypical people should not be made uncomfortable by the presence or needs of others, people experiencing the lived realities of their unconventional bodies must “hide” and “control” these human bodily functions to be accepted within their communities.

## Observation Findings

During my observations I found myself often questioning “*why would they do that?*” or thinking “*that’s not how I would do it*” however, I quickly reminded myself to set my reflexivity aside. I had to remind myself that “it is important to bear in mind that the actions of all parties of care interaction are necessarily affected by policy level decisions and governance...” (Murphy & Dingwall, 2001; Young, 1997, In Mietola, Miettinen, & Vehmas, 2017. Pp. 271) and often their actions are because of various policies and procedures they are trained by. However, I realized that these were important occurrences that I needed to note to adequately represent the complexity and interdependency of actions while taking into account the varying positions and views (Murphy & Dingwall, 2001; Young, 1997, In Mietola, Miettinen, & Vehmas, 2017.).

Observations were a challenge for me because of my experiences working in the field, specifically, at one program where I was previously employed. As challenging as the observations were for me to remain neutral, they were very crucial pieces of data that unearthed barriers detrimental to meaningful program participation.

### **Theme: Individualized Programming**

While observing, I became aware of the lack of individualized planning within several community programs. Although each program maintained the dignity and respect of the participants, this does not replace programming. There were multiple instances where participants were left waiting for the activity to finish because the activity was not meaningful for them or adapted to their abilities. An example of this was when Keira was attending a day program. This program is a recreation and leisure day program designed to socially engage all participants.

*We spent the morning wandering around the mall and returned to the center to eat lunch. Keira quickly ate her lunch and sat waiting for the other participants and staff to finish. While sitting she began repeating “lets go for a walk”.. no one acknowledged this. Eventually Keira got up and began wandering around the area.*

*Once everyone finished eating we went into the backroom and the staff member decided we would all make “Mothers Day” cards. A staff member pulled out the craft bins and set chairs around the table; Keira was walking around the room looking in the mirrors while fidgeting with a plush cookie monster she had carried into the room. A staff got all the other participants situated around the table and then gestured for Keira to take a seat at the table. Keira sat in the chair for about 2 minutes while the staff attended to the other participants and then got up and went and stood beside another participant. She began walking around the room again and found a plastic doll and a bead necklace, she began tapping the beads on the dolls plastic face listening to the sound; she then made a fist and hit her leg. Staff then approached her and asked her to pick a colour of construction paper she would like to use to make her card; Keira walked away and came over to where I was sitting in the corner and tried to take a seat on the chair between me and a bookshelf. Staff were busy helping the other participants so after Keira was with me for a few minutes, I stood up and walked with her back to the craft table and pulled out a chair. When I did this a staff member decided to turn on the stereo and “Hello” by Adele was playing, she sat in the chair swaying her body and laughing. She sat in the chair listening to music until everyone was done their crafts.*

A similar observation was made with Adam while at a summer day camp. The summer camp is a day full of various recreation and physical activities. On this day, the camp started outside at a park. The weather was warm, a little muggy and humid with overcast skies and no wind.

*When the yoga instructor arrived, Adam's staff turned to A and said "Look, yoga time!".. "C'mon.. yoga time!".. "let's go".. Adam did not budge. Eventually the staff and camp director lifted him to his feet and he began walking with them over to the yoga mats. Once they got to the yoga mats, he quickly sat down with his legs crossed, holding his toy in one hand and resting his head on his hand waiting for the rest of the group to arrive.*

*Once the rest of the group was there, the yoga instructor introduced herself, asked if anyone had done yoga before; he sitting with his legs crossed and his back to the instructor. Everyone began going through the yoga poses, he was still sitting with his back to the instructor and now laughing. The staff member working 1:1 with Adam began demonstrating the poses trying to get him to copy; he quickly turned and twisted his body away from her and brought his knees up to his chest. The staff member then tried to do co-active movement with him by lifting and moving his arms for him, he pulled away and remained sitting with his knees pulled into his chest. He then scooted away from the staff member and closer to the yoga instructor until he was sitting beside her on her mat, knees still pulled into his chest, with music player tapping it against his face, he then began watching her go through the poses. As the staff member left him to sit and watch, he slowly let his legs fall to the sides and returned to a crossed leg position, still listening to his music player. He remained sitting in this position on the yoga mat for the rest of the session.*

In both situations above, the participants' personhood was respected; however, they were not engaged in the activity. They were not given an adaptation or a different option rather they sat and waited for the rest of the group to finish. Each of these participants was in similar situations on several different occasions.

**Theme: *Who's Working Today?***

Two of my three participants had different staff each time I observed them in their programs. Each time I arrived, I was greeted by different staff members and told they were going to be working with the participant that day. At my last observation for each participant, I approached a staff member and asked why there was always different staff. At one program I was told that most of the participants have a specific staff member each session; however, this one participant often shows different “behaviours” with different people, so they continuously switch people around to see what he does. Another program told me that they purposely switch staff weekly, this way the clients do not get use to the same person and “this helps them learn to communicate with different people” (Program staff).

**Theme: *Programming Insights and Supports***

While observing these interactions, there were several insights I gained regarding different instructional strategies and program facilitation techniques. I observed several techniques that were ineffective and others that were very effective and engaged the participants. Rapport seemed to have a significant impact on the participants. Knowing the participants and understanding their non-verbal gestures and communication were crucial for meaningful engagement. An example of this was at an adaptive martial arts program:

*Today I attended an adaptive martial arts program to observe Chester. The instructor has worked with him for a couple years now and has built a strong rapport with him. During my first observation, the female instructor worked 1:1 with Chester, today she has a male volunteer working with him. While observing today there were a few times where Chester became anxious and would show this by groaning, pinching his arm and “darting” away from the activity, this often occurred when Chester was left waiting for the next task from the male volunteer. Each*

*time he began to groan, the instructor would come over and sing to him and he would become quiet, watching her and then would finish the activity.*

This instructor had taken the time to get to know Chester and understand his form of communication. She works with him each week and can support him to complete the activities and be fully engaged in the program. Another important facilitation technique is the ability to provide 1:1 support to participants who require more assistance. There were numerous situations throughout my observations where a participant was not meaningfully engaged in activities because of the lack of staff. My observations reflect those stated by Mietola, Miettinen, & Vehmas (2017), who explains that the limited number of staff in program settings often results in participants who have higher needs spending periods of time waiting for a worker to involve them. As a result, many participants spend much of their time waiting for the support they need to participate.

Lastly, one program I observed would take each task and break it down into smaller stations. By doing this I was able to see the individual participate within the group however, the activities were adapted to his abilities and he was supported 1:1 while completing each of these tasks. These strategies were very different from what I observed in the other programs. While observing this program, I quickly noticed that the staff to participant ratio was low, but all participants were actively engaged in meaningful programming the entire time they were there. Specifically, observing this one participant who is often quite anxious and tends to run away from activities when left disengaged, I was quite surprised with how few times he ran away and how few self injurious gestures he exhibited.

## **Lifeworld Existentials**

Lifeworld existentials give structure to the mundane experiences of these participants' lives (Van Manen, 1990). Existential exploration of these experiences permit a more robust description of the participants' lived world to share the complexity of these mundane activities. Here I will further break down the observation themes into the existential categories of *lived body, lived time, lived space and relation*.

### ***Lived Body***

Each participant experiencing Autism in this study does not use words as their main form of communication and therefore, much of their communication is done through body movements and gestures. In the example above of Keira with the Mother's Day craft, she expressed her interest in the activity through her body movements. By walking away and moving around the room, it was evident that Keira was not engaged in the activity. However, when the staff turned on the radio and the music began to play, Keira remained seated and swinging her body back and forth, laughing and enjoying the music. I observed Keira's bodily expressions as forms of communication, how she moved her body and where she moved her body gave substantial understanding of her preferences. Like Keira walking away from the group activity, Chester exhibited boredom and anxiety through his explosive, darting and arm flapping. When left waiting for the next task when working the male volunteer, Chester expressed his discomfort through his body movements and gestures. Lastly, Adam expressed his comfort and discomfort through his body positioning. When the staff working with Adam were asking him to participate in yoga, Adam turned his body away from the staff and would sit with his knee's pull tight into his chest. When the staff left him alone and participated in yoga without him, Adam adjusted his and moved into a relaxed, crossed leg position.

### ***Lived Time***

Everyone perceives time differently. How someone is feeling in a situation greatly impacts how they perceive time. When reflecting on my observations of Keira, I can recall several situations where time was perceived by Keira differently than her peers. For example, there were several occasions where Keira became bored waiting for the group to finish a task (i.e. lunch, taking a break at the mall) or the group was engaged in an activity that Keira was not interested in (i.e. craft). In these moments, Keira would sit with the group for a couple minutes before popping out of her chair and repeatedly scripting “lets go for a walk”. When Keira would say this, staff did not respond to Keira however, through my observations, it was evident that Keira was bored with the task that her peers were still engaged in. Keira does not like to wait and when she has a period where she is bored or disengaged, Keira became agitated and would repeat “lets go for a walk”. While others in her group would stay at the activity, content for long periods of time, Keira would become agitated and restless after a few minutes. Similarly, in the story discussed earlier with Chester, his felt time was much different than the volunteer he was working with. The volunteer would leave him with unplanned time or breaks between activities which would result in Chester feeling anxious and uncomfortable therefore, he would dart away from the activity at a fast, and sudden pace.

### ***Lived Space***

Like the varying perceptions of time, space is highly subjective and ever changing. For Chester, space is a highly significant lifeworld experience. Upon entering any space, Chester will walk in touching each and every crease, and corner of the walk way and doorway leading into the area. This is a ritual Chester has developed over the years and I observed it through my observations. One highly significant note I made when rereading my observation notes was that



Chester did not do this ritual when entering the Martial Arts studio, neither of the time's I was there. I did not see him enter the building however, when entering the dojo, he did not do this. However, when observing him at the trampoline park with his respite worker, he did this ritual on the way into the building and on the way out. When reflecting on these occurrences, I came to the realization that this ritual is probably a calming coping mechanism for anxiety entering different spaces. This is Chester's way of gaining control of the unknown that he is about to enter. Through my observations, I believe that Chester does not complete this ritual when entering the dojo because he has been asked to bow at the door way before entering and before exiting the space. This martial art's tradition of bowing has given Chester a sense of comfort and routine that he can trust will happen each time he enters that space, hence decreasing his anxieties towards entering the area.

### ***Lived Relation***

As human beings we interact with other people each day. Some of these interactions develop into relationships, others remain less personal however, each of these interactions change our lived world. A well-known stereotype of autism is that autistic people do not wish to have social interactions and prefer to live in isolation however, this is not always the case, especially not for the participants in this study. During observations, the desire for social interaction was subtly expressed and later in the interviews, each caregiver brought up their child's desire for social interactions. When observing Adam in the day program and at the day camp, I noticed that there was another young adult that also attended both of these programs and on multiple occasions, Adam would get up and move to be near him. While observing the day program, there was a time where the other participant was laughing and running around in the water and Adam was watching him, intently and then began laughing and banging his back

against the wall. A similar situation happened with Keira, where on different days, she would get up and go to stand near another participant in her group. To many people, these subtle interactions may not seem relational however, for participants who experience autism and do not use words to communicate, this is their way of communicating and developing relationships.

Like the relationships these participants are developing with peers, I also observed their relationships with objects. For example, Adam has a music player and other objects which he always carries with him, he uses these objects as a form of coping mechanism to self calm during heightened moments. As well, during my observations I noticed that when Keira would enter each room at the day program, she would pick up a toy or object, hold onto it while in the room, carry it to the next room and then switch it off with a new toy or object she found in that room. Keira formed her own relationship with the toy in each room, whether she used them as a form of transitioning from one task to another, or simply as something to fidget with, this became a meaningful relationship with her and the object.

In contrast, a different form of relation was noted regarding the ever-changing staff at the programs. When considering that these programs continuously have different staff working, it may be hard for the participants to fully develop a strong rapport with the staff. Similarly, a relation pattern discussed by staff was Adam's *private meanings* with various staff. Adam seems to have his own *private meanings* with each staff which results in him developing different patterns and rituals depending on who he is working with and therefore the program he attends felt it was better to continuously change the staff that worked with Adam.

These descriptions express the complexity of the lived world experienced by these participants. Considering they do not use words to communicate, it is crucial to further look into each experience through these existentials to give a greater understanding of their stories being

shared. Although I have broken these descriptions into parts, it is evident that each of these existentials occur in unity of the others and together develop a robust description of their lived world.

## Chapter 5: Discussion

*“... you have these higher need individuals that can’t access resources because even the resources that are touted as being wonderful.. they don’t want you... they don’t want you in their day program because you’re incontinent.. they don’t want you because you are too much work.. they want the easier people and we’ve had that happen with the odd worker too.. where they are great with some developmentally disabled people that can go to the Blue Jays game ... they have fun but if you’re peeing on the floor and can’t do these things... you’re too much work and I don’t want to service you” (Anna and Anthony)*

### What experiences are constituted as barriers?

#### “The Professionals”

As discussed in the findings, it was evident that caregivers were often frustrated with the support they received from staff and professionals in the field. These findings are like those discussed earlier which identified unqualified staff (Obrusnikova & Cavalier, 2011; Jones, 2013; Taub & Greer, 2000; WHO, 2015; Moran & Block, 2010) and not enough staff (Schleien, Germ, & McAvoy, 1996) as major barriers to program participation. Specifically, one caregiver described situations where the staff were unable to support the individual during a distress episode resulting in calling the parents to come pick him up and the staff placing the responsibility on the individual.

Staff being unprepared and unable to adapt to the individual was a significant barrier to participation. This dilemma was discussed in interviews and noted during observations. While completing observations, I was pleased to see how staff respected the individual and protected their dignity and safety which was like previous research that noted staff attitudes were not viewed as a barrier (Schleien, Germ, & McAvoy, 1996). In contrast, caregiver interviews did indicate that from their perspective, staff attitudes have been a significant barrier in the past

because the staff feel the youth is “too much work” or they are “not compliant”. These findings are probably incongruent because I was only at each program for a couple days to observe which does not give a strong perspective of the overall situation. As well, I was there to observe the activities the youth participated in, I was not on the receiving end of the services and therefore, the caregivers’ experiences are much more valuable than my own and give a greater understanding of the barriers they experience.

Regarding my observations, as pleasing as it was to see staff respecting the individuals’ dignity, we still have a long way to go because this does not replace programming. Often participants, such as the example of Keira during the craft time, are left disengaged from activities because they need the activity adapted to their needs and preferences. In one study that looked at parents’ perspectives on the inclusion of children in community recreation programs, the parents recommended that staff receive training to “learn how to accommodate all children and develop strategies for including persons with disabilities in community recreation programs” (Jones, 2003). Although these findings are with children, I believe staff do need further training to accommodate all participants meaningfully. However, in the example with Kiara, I believe this situation was due to the limited amount of staff available. This program was run with two staff and five participants which while manageable, did not lead to meaningful engagement. Staffing constraints has been noted as a significant barrier to inclusive community programming in previous research (Schleien, Germ, & McAvoy, 1996).

### **The “Out of Control” Body**

*“It can be embarrassing when the lack of awareness is bathroom related. And when your body does not feel, or only begins to feel the need to use the bathroom when it is already too late, incidents, or accidents, happen” (Sequenzia, 2013).*

The findings in this study emphasized the barriers many families and individuals experience because of the unquestioned primacy of normalcy. Many families are faced with concern for their loved one's dignity because of the discrimination they face in the community from bodily functions being deemed as socially unacceptable. Our society views these lived experiences as something to be "suffered" "in private"; the public world is the world of strength, the positive (valued) body, performance and production, the non-disabled, and young adults. Weakness, illness, rest and recovery, pain, death, and the negative (devalued) body are private, generally hidden, and often neglected" (Wendell, 1996, pg. 40) from our society.

Our lived body is our initial point of interactions with one another; it is how we present ourselves in the world. Our lived body is viewed differently depending on the way another person looks at it (Van Manen, 1990. Pg. 104). Due to the strong impact of normalcy and ableism, people are quickly drawn to "different" bodies and will view them through a pejorative, comparative gaze whether this is intentional or not.

Our society is built around the *personal tragedy model* which views disability as an individual problem in need of repair (Cameron, 2014, p. 116-119). Due to this dominant perspective, "from an early age disabled people undergo training to experience their bodies as challenges to be struggled with in pursuit of normality" (Cameron, 2014, p.108). Individuals grow up believing their bodies are the problem that they must hide from society, their "problems are identified not with the fact that their access requirements have not been addressed, but with their 'faulty' bodies" (Cameron, 2014, p 18). Listening to caregivers describe their experiences with being limited with where they can go because of the fear of their adult child having an "accident" because they are incontinent or being unable to eat at restaurants because of needing their food pureed, sensory difficulties or being unable to wait for significant periods of time are

all situations that can be accommodated. Why can't we ask restaurants to puree food? Why can't we order plain meals with minimal sauces or spices? Why are there not more family washrooms? Many of these situations occur because many people have grown up believing these are things they must find solutions to themselves and these are situations that are not socially acceptable. Our "world is organised into a hierarchy in which the non-disabled body is advantaged, and the impaired body is judged as incompetent" (Cameron, 2014, p.19). Our society needs to make a shift to begin accepting all bodies and all needs. If restaurants offered the option to have your food pureed, then many people would not be "disabled" when going to restaurants. If more washrooms were "family" then caregivers would be able to assist the youth with toileting while out in the community. Through this lack of acceptance and accommodations in society we alienate those who need these accommodations. Cameron (2014) clearly explains that "alienation involves a concerted effort to brush out of the picture, at both personal and social levels, the difficult and challenging, odd and inconvenient aspects of what being human is about, and to focus instead on keeping up appearances; on maintaining a narrative which says that 'all is well with us'." (p. 11).

Similarly, the challenge of being amongst a crowd is a common negative experience for many people, including people that do not experience ASD. For this study, crowds are being viewed as not only a physical experience but as *lived space*. Van Manen (1990) explains how an individual will become the space they are in simply by how it is felt. The experience of crowds is anxiety provoking and over stimulating for all participants in this study which may be from the physical distance felt between them and others and it may also be impacted by the feelings of being an 'outsider' and being alienated in a group of people. The caregivers expressed this and I also observed this while observing a participant in a program where they went to the mall. I

noted that as we walked around the mall, I remember many people turning in their chairs to look at us as well as the different types of looks we were receiving. These simple actions people make have a big impact on the overarching issue among our society. The problem is that people are stared at if they look or act *different*. Individuals are stigmatised because of their physical or behavioural characteristics that deviate from the societal norm. This stigmatization occurs as a response to the “social awkwardness and discomfort they provoke in normals” (Thomas, 2007. In Cameron, 2014, p. 147). Many people experiencing disability have grown up having to learn how to conform to society to fit in, but this is only because our society has made them feel they need to change to make others more comfortable. This may be the reason for the discomfort felt by the participants when in crowds because they are stigmatised and alienated. In my findings I used a quote in *community vs. crowd*, where the caregivers explained how their son is noticeably more comfortable around other people with unconventional bodies and they feel it is because he can relax and be himself. Our society has forced many individuals who experience disability to feel uncomfortable with being themselves in community settings and therefore they are forced to adapt who they are to conform, because of this, it is no wonder why he is noticeably happier when with other people experiencing disabilities like him.

In conclusion, stigma and alienation are two prominent factors that have led to barriers to community participation. Individuals are unable to be themselves when out in the world and must hide their bodily experiences to conform to the norm of our society. People are unable to have a meal with family and friends at a restaurant because of fear of alienation for having their food pureed and they are stigmatised when in groups of people making them anxious and uncomfortable proving that the personal tragedy model is still the dominant model in society.



## **Which barriers experienced have the greatest impact on participation in community programs?**

After completing analysis, it was quickly evident which barriers discussed have the greatest impact on participation in community programs. The major finding that seemed to have the greatest impact on participation in community programs was related to the professionals. As previously discussed, the lack of staff, support and training they receive has a significant impact on the participants having meaningful, engaging experiences. Staff being unprepared to adapt to the needs of individuals with complex needs is a challenging barrier to address. These findings were like Schleien, Germ, and McAvoy (1996) which found staff have the greatest responsibility regarding inclusion of participants and often they do not receive the training they need to implement “recommended professional practices”. We could simply recommend that staff must learn how to accommodate all abilities however, there is very little research conducted with individuals with complex needs, specifically individuals with Autism who do not use words to communicate. Therefore, it is no wonder why professionals are often unprepared and lack the support and resources. After looking through the literature and realizing that most of the research in programming is with children and/or with people experiencing “high functioning” Autism, I cannot help but question if programming is inadequate? If programs are generalizing these findings to all people with Autism, then it is no wonder why the staff are unable to accommodate individual needs and adapt the programs. These professionals are often well meaning and care for the individuals they support; however, the lack of training and experience they have greatly impacted their work because many of these professionals have received care giver training however they have not received adequate, individualized programming training.

## **Can Mark Priestley's 6 principles of emancipatory research be applied to the research process?**

### **“Is it unethical to be ethical?”**

When beginning this study, I was naïve. I read Mark Priestley's 6 principles and thought it would not be difficult to implement them in my research process because they were in line with my values and perspective. I assumed I would have to adapt my data collection methods and focus on their strengths to be able to include their “voices” in the study but again, I did not think it would be that difficult because I *know* them, and I know how they communicate. However, from the beginning of this study I acknowledged that I am an outsider and I cannot speak to someone else's experiences. I acknowledge that even if I had the time and was able to consult with the participants in the end I am still an outsider and therefore, true emancipatory research was already at a disadvantage. Although I was aware of some challenges beginning the study, what I did not expect was that the biggest challenge was not with adapting methods but with the research process. I was prepared to adapt to my participants and do what I needed to include their perspective and stories in the study however, I was not prepared for how underestimated they would be. From the beginning of this study I was quickly faced with the reality that conducting true emancipatory research with this group would not be possible. I was quickly informed about how much of our policies and procedures are still focused on the “capacity” and this unquestioned starting point for many individuals. If an individual does not use words to communicate, their ability to understand was quickly questioned and my position as a researcher and as a professional was questioned.

From the initial phases of this research process, we were faced with barriers. When applying to the REB regarding the research process and the participants I would like to include, I

was challenged with several obstacles, all of which questioned their abilities and my multiple roles in this field. I had chosen this group primarily because they are often excluded from research, therefore program practices for them are not research based and do not benefit them. I also chose this group because I have experience working with them and I can accommodate their needs and communicate effectively. However, to my surprise, it was brought to my attention that this rapport I have established with potential participants was considered a conflict of interest. Specifically, I was hoping to include a participant with whom I have worked closely with for the past two and a half years but this was identified as a conflict of interest and I was told that I cannot “cannot simply assume that the potential participant who is [my] client will understand and be able to differentiate [my] role as researcher from [my] role as a respite worker” (REB). In the end, I was recommended to exclude this participant from my potential sample. However, other contemporary researchers have expressed “that it is actually unethical to exclude persons with PIMD from research that could provide insights about their subjective experiences, and about how to promote their well-being” (Tuffrey, Wijne, Bernal, & Hollins, 2008, p. 188, In Mietola, Miettinen, & Vehmas, 2017, p. 264). Having rapport with my participants was initially viewed as a benefit to the study because I did not have to consult their caregivers to understand their unique forms of communication (Mietola, Miettinen, & Vehmas, 2017). Existing research states “...that human relationships should be sustained over time in special needs education, given the value of long-term interaction in detecting and acknowledging contrasting movements that express the wordless perspectives of students with severe and multiple disabilities.” (Evensen and Standal, 2017). The significance of building rapport to understand individual modes of communication has been reiterated in other studies with individuals who do not use

words to communicate (e.g. Davis, Watson, & Cunningham-Burley, 2008; Pockney, 2006; Simmons & Watson, 2014).

Due to these various challenges, I was unable to use Priestley's 6 principles for emancipatory research working with these participants, however, I believe there is still hope for future studies to follow these principles, not as criteria or a check list but more as values we hold with us while conducting the study. Just because these participants do not use words to communicate, I do not believe they should be left out of emancipatory research. My findings have shown me that although I was unable to follow the principles, I suggest not limiting yourself when trying to follow Priestley because these principles can be adapted to include higher need individuals. An article written by Zarb (1992), explains how true emancipatory research must focus on two main principles, empowerment, and reciprocity (Zarb, 1992. In Martin, 2015). By keeping these principles in mind throughout the process and always questioning who the research is benefitting, you can include a variation of emancipatory research. There is still a significant amount of hope within this field to conduct emancipatory research and include the "voices" of individuals with complex needs simply by ensuring the study is designed to benefit them and in (non-traditional) consultation with them. By focusing on principle 3, *"the willingness only to undertake research where it will be of some practical benefit to the self empowerment of disabled people and/or removal of disabling barriers"* and principle 6, *"the willingness to adopt a plurality of methods for data collection and analysis in response to the changing needs of disabled people"* you can make a significant contribution towards emancipatory practices including participants with complex needs. Like Chappell (2000) who indicates that "it is the design and intentions of research that are defining elements of emancipatory research" (Chappell, 2000. In Martin, 2015. p. 210), although this study was not

successful in following all of Priestley's principles, the design and intentions of the research were in line with emancipatory research. This study followed several principles, specifically Principle 3 because this study was focused on addressing barriers to community program participation and inadvertently turned to also focus on barriers to participation in research. By addressing the barrier associated with participation in research, I hope to raise awareness of these oppressive practices in hopes of change for future studies.

## Limitations and Future Directions

Primarily, I think my greatest limitations were time and policies. Due to my limited time to complete my study within the constraints of my master's degree, I did not have time to incorporate some aspects of the study I had originally hoped to include. I feel it would be beneficial to create a longitudinal study to include more observations of the participants in various community programs and to include service providers to see where this lack of adaptability begins. I would also recommend a future study to include non-traditional interviews with the youth participants to include their feelings regarding different barriers in community program participation. These interviews can be done using visual prompts, such as photos of places and activities as well as emoticons to allow them to choose which emotion they relate to the experience. I also suggest these interviews should be conducted multiple times to see if their responses change.

In contrast, another future direction would be to conduct research *with* REB's and granting agencies as these are two groups who inadvertently make including participants with complex needs in research very challenging due to policy and procedures. By identifying these challenges and procedures, we can educate ethics boards about inclusive, adaptive practices they can incorporate into their reviews. Further researching these policies and exclusionary practices would be greatly beneficial for future researchers as well as for the participants who are impacted by the barriers to services they receive.



*Figure 1: Research implications*

As seen in the image above, addressing these ethical constraints to research can have a collateral, cumulative, compounding effect resonating not only within research but with the services the participants receive. Developing more inclusive policies directed towards including people with complex needs who do not use words to communicate will permit more research on underserved groups. There currently are not enough evidence-based practices to help many individuals participate in meaningful, active leisure and meaningful structured programming. Creating more inclusionary research practices will have a greater, long term impact not only within research but within programming. Increasing the production of authentically inclusive research will result in better staff training and more inclusive, meaningful programming.

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## Appendices

### Appendix A. Ethical Clearance



**Brock University**  
Research Ethics Office  
Tel: 905-688-5550 ext. 3035  
Email: reb@brocku.ca

Social Science Research Ethics Board

#### Certificate of Ethics Clearance for Human Participant Research

DATE: 8/10/2017  
PRINCIPAL INVESTIGATOR: CONNOLLY, Maureen - Kinesiology  
FILE: 16-315 - CONNOLLY  
TYPE: Masters Thesis/Project STUDENT: Demi Toms  
SUPERVISOR: Maureen Connolly  
TITLE: A Week in the Life: A Phenomenological Study Describing Barriers in Daily Life Experienced by Three Transition Age Youth with Autism Spectrum Disorder and their Caregivers

#### ETHICS CLEARANCE GRANTED

Type of Clearance: NEW

Expiry Date: 8/1/2018

The Brock University Social Science Research Ethics Board has reviewed the above named research proposal and considers the procedures, as described by the applicant, to conform to the University's ethical standards and the Tri-Council Policy Statement. Clearance granted from 8/10/2017 to 8/1/2018.

The Tri-Council Policy Statement requires that ongoing research be monitored by, at a minimum, an annual report. Should your project extend beyond the expiry date, you are required to submit a Renewal form before 8/1/2018. Continued clearance is contingent on timely submission of reports.

To comply with the Tri-Council Policy Statement, you must also submit a final report upon completion of your project. All report forms can be found on the Research Ethics web page at <http://www.brocku.ca/research/policies-and-forms/research-forms>.

In addition, throughout your research, you must report promptly to the REB:

- a) Changes increasing the risk to the participant(s) and/or affecting significantly the conduct of the study;
- b) All adverse and/or unanticipated experiences or events that may have real or potential unfavourable implications for participants;
- c) New information that may adversely affect the safety of the participants or the conduct of the study;
- d) Any changes in your source of funding or new funding to a previously unfunded project.

We wish you success with your research.

Approved:

Ann-Marie DiBiase, Chair  
Social Science Research Ethics Board

**Note:** Brock University is accountable for the research carried out in its own jurisdiction or under its auspices and may refuse certain research even though the REB has found it ethically acceptable.

If research participants are in the care of a health facility, at a school, or other institution or community organization, it is the responsibility of the Principal Investigator to ensure that the ethical guidelines and clearance of those facilities or institutions are obtained and filed with the REB prior to the initiation of research at that site.

## Appendix B. E-mail Script

Dear \_\_\_\_\_

Hi, my name is Demi Toms. I am a Graduate student working with Dr. Maureen Connolly at Brock University in the Faculty of Applied Health Sciences. I have been volunteering with the Saturday SNAP and ASD Summer Movement Camp programs for a little over 4 years and I have been extensively involved in the program planning and instruction for the teen and young adult participants. I am sending this e-mail to invite you and your teen to participate in my research study.

The purpose of this study is to understand potential barriers experienced by three transition aged youth with Autism and their caregivers in a ‘typical week’.

### Youth Participation

Should you and your teen choose to participate, I would like to attend any physical or recreational program the teen is involved in. By attending the program, I will arrive at the facility and stay out of the facilitation of the program to simply observe. I would like to do this because I have had time to observe your teen at the Saturday SNAP program and I acknowledge this program is heavily structured and designed for the success of the participants. By going to a community-based program, I will gain insight into their interactions in a different program setting.

For this part of the study, I would ask for you to send me a weekly schedule of the programs the teen is involved in that I can attend that will not be disruptive to the participants or the facility.

After I have observed the teen in a program, I will then interview them individually, using an alternative visual communication system. The alternative visual communication system will involve pictures of activities (i.e. swimming, shopping, eating, etc.) and other observations I make at the program. I will also be using emotion images (i.e. happy, sad, angry, etc.) to try and understand how the participant feels about various aspects of the program/ activities.

### Caregiver Participation

Should you choose to participate, you will be asked to participate in one interview, approximately 60 minutes, to discuss what a ‘typical week’ is like for you and your child. Following this interview, you are welcome to schedule a second follow-up interview, if desired.

I have attached the official letter of invitation to this e-mail with more information regarding ethic’s clearance, confidentiality, and so forth. Please feel free to look this over and contact me with any questions.

Lastly, your decision to participate or decline my invitation will have no effect on your child’s participation in the Saturday SNAP program.

Sincerely,

Demi Toms

## Appendix C. Letter of Invitation

**Title of Study:** A Week in the Life: A Phenomenological Study Describing Barriers in Daily Life Experienced by Three Transition Age Youth with Autism Spectrum Disorder and their Caregivers

**(Student) Principal Investigator:** Demi Toms, BKin, MA Candidate (Health and Physical Education), Brock University

**Faculty Supervisor:** Dr. Maureen Connolly, Professor, Department of Kinesiology, Brock University

I, Demi Toms, Master of Arts Candidate, from the Department of Applied Health Science, Brock University, invite you to participate in my research project entitled “A week in the life”

The purpose of this research project is to understand the experiences of three transition aged youth with Autism in a ‘typical week’. Should you choose to participate, you will be asked to participate in one or two interviews, each approximately 60 minutes, to discuss what a ‘typical week’ is like for yourself and your child. As well, I will also conduct three observations of your child at a community program or activity that they attend on a weekly basis.

This research has the potential to benefit other families within the Autism community. This study hopes to raise awareness of living with ASD to aid in the development and implementation of accessible community programs.

If you have any pertinent questions about your rights as a research participant, please contact the Brock University Research Ethics Officer (905 688-5550 ext 3035, reb@brocku.ca)

If you have any questions regarding the study, please feel free to contact me (see below for contact information).

Thank you,

**Demi Toms**

BKin, MA Candidate (Health and Physical Education)

Brock University

demi.toms@brocku.ca

**Dr. Maureen Connolly**

Professor, Department of Kinesiology

Brock University

mconnolly@brocku.ca

This study has been reviewed and received ethics clearance through Brock University’s Research Ethics Board [16-315-CONNOLLY]

## Appendix D. Caregiver Informed Consent

Date:

Project Title: A Week in the Life: A Phenomenological Study Describing Barriers in Daily Life Experienced by Three Transition Age Youth with Autism Spectrum Disorder and their Caregivers

**(Student) Principal Investigator (PI):** Demi Toms, BKin, MA Candidate (Health and Physical Education)

Department of Applied Health Science  
Brock University

289-213-6427;

Demi.toms@brocku.ca

**Faculty Supervisor:** Dr. Maureen Connolly, Professor

Department of Kinesiology

Brock University

(905) 688-5550 Ext. 3381;

mconnolly@brocku.ca

### INVITATION

You and your child are invited to participate in a study that involves research. The purpose of this study is to understand barriers experienced by transition age youth with Autism Spectrum Disorder in a 'typical week'.

### WHAT'S INVOLVED

As a participant, you will be involved in one or two (if necessary) interviews to discuss a 'typical week' for you and your child/dependent. The initial interview will take approximately 60 minutes of your time. If necessary, a follow up interview will take approximately 30 minutes. The interview will be recorded using an audio recording device and the researcher will be taking notes throughout the interview. The participant will decide between their home or a private office at Bridges for Autism, Pen Centre location for this interview. Please note, if the participant chooses to conduct the interview within their home, it must be noted that the researcher is under legal duty to report any risk of harm/ abuse they may witness.

### POTENTIAL BENEFITS AND RISKS

Possible benefits of participation include sharing your stories and experiences with others to raise awareness about living with ASD. It is anticipated that this research may contribute to a more accessible community for your family, and other's living with ASD. There are no known or anticipated risks associated with participation in this study.

## **CONFIDENTIALITY**

This study is being conducted within a small community and therefore, confidentiality may be compromised however, I will ensure confidentiality is protected from a broader public audience.

Each interview will be recorded and will only be shared between the researcher and interviewee. Once each interview has been transcribed, the audio recording will be deleted.

Data collected during this study will be stored on the student principle investigators personal computer which is passcode protected. Data will be kept until the study is defended, at which time all data will be deleted from the personal computer.

Access to all data will be restricted to Demi Toms and Dr. Maureen Connolly.

To ensure confidentiality, you and your child's name will not appear in my thesis or any documentation from this study. Each participant will be given a pseudonym in which they will be referred to. With your permission, some confidential quotes may be used.

## **VOLUNTARY PARTICIPATION**

Participation in this study is voluntary. If you wish, you may decline to answer any questions or participate in any

component of the study. Further, you may decide to withdraw from this study at any time and may do so without any penalty. Should the participant choose to defer participation in this study, their participation in the Saturday S.N.A.P program will not be compromised.

## **PUBLICATION OF RESULTS**

Results of this study may be published in professional journals and presented at conferences. If this study is published and/or presented, your pseudonyms will be used.

## **CONTACT INFORMATION AND ETHICS CLEARANCE**

If you have any questions about this study or require further information, please contact Demi Toms or Maureen Connolly using the contact information provided above. This study has been reviewed and received ethics clearance through the Research Ethics Board at Brock University [16-315-CONNOLLY]. If you have any comments or concerns about your rights as a research participant, please contact the Research Ethics Office at (905) 688-5550 Ext. 3035, reb@brocku.ca.

Thank you for your assistance in this project. Please keep a copy of this form for your records.

## **CONSENT FORM**

I, \_\_\_\_\_ will participate in this study described above. I have made this decision based on the information I have read in the Information-Consent Letter. I have had the opportunity to

receive any additional details I wanted about the study and understand that I may ask questions in the future. I understand that I may withdraw this consent at any time.

Name: \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

## Appendix E. Caregiver Consent Form on behalf of Dependent/Youth in your Care

Date:

Project Title: A Week in the Life: A Phenomenological Study Describing Barriers in Daily Life Experienced by Three Transition Age Youth with Autism Spectrum Disorder and their Caregivers

**(Student) Principal Investigator (PI):** Demi Toms, BKin, MA Candidate (Health and Physical Education)

Department of Applied Health Science

Brock University

289-213-6427

Demi.toms@brocku.ca

**Faculty Supervisor:** Dr. Maureen Connolly, Professor

Department of Kinesiology

Brock University

(905) 688-5550 Ext. 3381;

mconnolly@brocku.ca

### INVITATION

You and your child are invited to participate in a study that involves research. The purpose of this study is to understand barriers experienced by transition age youth with Autism Spectrum Disorder in a 'typical week'.

### WHAT'S INVOLVED

As a participant, youth participants will be observed at a community program or activity they attend. The participant and caregiver will decide which program would be least impacted by having the researcher present.

These observations will be conducted on three different occasions, at the program chosen by the caregiver. Each observation will vary in length, depending on the program and/ or activity. The researcher will be there to observe and will have minimal to no interactions with the youth while they are attending the program. The researcher will be observing what activities the youth participates in as well as supports they receive.

### POTENTIAL BENEFITS AND RISKS

Possible benefits of participation include sharing your stories and experiences with others to raise awareness about living with ASD. It is anticipated that this research may contribute to a more accessible community for your family, and other's living with ASD. There are no known or anticipated risks associated with participation in this study.



## **CONFIDENTIALITY**

This study is being conducted within a small community and therefore, confidentiality may be compromised however, I will ensure confidentiality is protected from a broader public audience.

Each interview will be recorded and will only be shared between the researcher and interviewee. Shortly after the audio recorded interview has been completed, a transcript of the interview will be transcribed, and a copy will be sent to you electronically. This will give you the opportunity to confirm the accuracy of the interview and provide you with the opportunity to add or further clarify any information shared. During the observation process, the researcher may take notes. However, to ensure confidentiality, you and your child's name will not appear in my thesis or any documentation from this study. Each participant will be given a pseudonym in which they will be referred to.

Data collected during this study will be stored on the student principal investigator's (Demi Toms) personal computer which is passcode protected and a separate USB. Data will be kept until the study has been defended at which time the written documents will be shredded and all electronic and audio documents will be deleted. Access to this data will be restricted to Demi Toms (Principal Student Investigator), Dr. Maureen Connolly (Supervising Faculty) and members of the research study committee, who are professors at Brock University (Dr. Tim Fletcher, and Dr. Jae Patterson)

## **VOLUNTARY PARTICIPATION**

Participation in this study is voluntary. If you wish, you may decline to answer any questions or participate in any component of the study. Further, you may decide to withdraw from this study at any time and may do so without any penalty. Should the participant choose to defer participation in this study, their participation in the Saturday S.N.A.P program will not be compromised.

## **PUBLICATION OF RESULTS**

Results of this study may be published in professional journals and presented at conferences. If this study is published and/or presented, your pseudonyms will be used.

## **CONTACT INFORMATION AND ETHICS CLEARANCE**

If you have any questions about this study or require further information, please contact Demi Toms or Maureen Connolly using the contact information provided above. This study has been reviewed and received ethics clearance through the Research Ethics Board at Brock University [16-315-CONNOLLY]. If you have any comments or concerns about your rights as a research participant, please contact the Research Ethics Office at (905) 688-5550 Ext. 3035, reb@brocku.ca.

Thank you for your assistance in this project. Please keep a copy of this form for your records.

**CONSENT FORM**

I agree the teen in my care, \_\_\_\_\_ can participate in this study described above. I have made this decision based on the information I have read in the Information-Consent Letter. I have had the opportunity to receive any additional details I wanted about the study and understand that I may ask questions in the future. I understand that I may withdraw this consent at any time.

Name of child: \_\_\_\_\_

Your name: \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

## Appendix F. Organization Informed Consent

Date:

**Project Title:** A Week in the Life: A Phenomenological Study Describing Barriers in Daily Life Experienced by Three Transition Age Youth with Autism Spectrum Disorder and their Caregivers

**(Student) Principal Investigator (PI):** Demi  
Toms, BKin, MA Candidate (Health and  
Physical Education)

Department of Applied Health Science  
Brock University

289-213-6427;

Demi.toms@brocku.ca

**Faculty Supervisor:** Dr. Maureen Connolly,  
Professor

Department of Kinesiology

Brock University

(905) 688-5550 Ext. 3381;

[mconnolly@brocku.ca](mailto:mconnolly@brocku.ca)

### INVITATION

Your community facility is invited to participate in a study that involves research. The purpose of this study is to understand barriers experienced by transition age youth with Autism Spectrum Disorder in a 'typical week'.

### WHAT'S INVOLVED

As a site for research, your program/facility will be involved in the observation process of my research. I will be observing specific participants within your program/facility to see their interactions with employees, volunteers, program participants, and within the space. The data collected from these observations will be used to develop a greater understanding of their experiences within community settings.

### POTENTIAL BENEFITS AND RISKS

Possible benefits of participation include sharing experiences with others to raise awareness about accommodating individuals with ASD. It is anticipated that this research may contribute to a more accessible community for families, and other's living with ASD. There are no known or anticipated risks associated with participation in this study.

### CONFIDENTIALITY

This study is being conducted within a small community and therefore, confidentiality may be compromised however, I will ensure confidentiality is protected from a broader public audience.

Data collected during this study will be stored on the student principle investigators personal computer which is passcode protected. Data will be kept until the study is defended, at which time all data will be deleted from the personal computer.

Access to all data will be restricted to Demi Toms and Dr. Maureen Connolly.

To ensure confidentiality, you and your organization's name will not appear in my thesis or any documentation from this study. Each participant and organization will be given a pseudonym in which they will be referred to. With your permission, some confidential quotes may be used.

### **VOLUNTARY PARTICIPATION**

Participation in this study is voluntary. If you wish, you may decline to answer any questions or participate in any component of the study. Further, you may decide to withdraw from this study at any time and may do so without any penalty. Should the participant choose to defer participation in this study, their participation in the Saturday S.N.A.P program will not be compromised.

### **PUBLICATION OF RESULTS**

Results of this study may be published in professional journals and presented at conferences. If this study is published and/or presented, your pseudonyms will be used.

### **CONTACT INFORMATION AND ETHICS CLEARANCE**

If you have any questions about this study or require further information, please contact Demi Toms or Maureen Connolly using the contact information provided above. This study has been reviewed and received ethics clearance through the Research Ethics Board at Brock University [16-315 – CONNOLLY]. If you have any comments or concerns about your rights as a research participant, please contact the Research Ethics Office at (905) 688-5550 Ext. 3035, reb@brocku.ca.

Thank you for your assistance in this project. Please keep a copy of this form for your records.

### **CONSENT FORM**

I agree my organization, \_\_\_\_\_ can be used as a site for observations for research in this study as described above. I have made this decision based on the information I have read in the Information-Consent Letter. I have had the opportunity to receive any additional details I wanted about the study and understand that I may ask questions in the future. I understand that I may withdraw this consent at any time.

Name of Organization: \_\_\_\_\_

Your Name: \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

## Appendix G. Interview Guide

When did you first know your child has Autism?

Can you tell me about the process of your child's diagnosis?

Prompt: how old were they? How long did it take?

What is a typical week like for you and your child?

Prompts: -Do you use a weekly or daily schedules

- What affects does school have in a typical week?

- Does your child attend programs outside of school? If so, what kind of programs and how often?

What activities do you and your child do together?

Prompts: grocery shopping, go out to dinner, see a movie, etc.

What emotional experiences happen in a typical week?

Prompts: - frustration

-Happy

- Sad

- Anxious

What emotions are consistent over time and across/within contexts?

Prompts: - Are there any specific activities which result in the same emotion each time they are experienced?

- Can you describe an example?

## Appendix H. Observation Sheet

Type of program: \_\_\_\_\_

Length of program: \_\_\_\_\_

**Description of program** (sound, light, equipment, organization, smell, etc.):

### Professionalism

Attire (appropriate for the activity? Etc.)	
Interpersonal communication:	
Listening (to participant and to coworkers)	
Acknowledging/ Interacting with Participant	

Waiting/ pausing (for participants response)	
for Language used (appropriate activity and understanding)	
Activity/ task: developmentally appropriate? Adaptations?	

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**Participant Interactions**

Gestures and body language: During interpersonal interactions	
During planned activity	
During unplanned time	



Vocal/ Verbal (words, sounds, scripts, etc.)	
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**Participant use of space: Movement Map for Unplanned time**

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## Appendix J. Analysis

